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Correlates of Human Papillomavirus (HPV) Vaccine Acceptance in Appalachian Tennessee

A dissertation

presented to

the faculty of the College of Public Health

East Tennessee State University

In partial Fulfillment

of the requirements for the degree

Doctor of Public Health with a concentration in Community and Behavioral Health

by

Oluwatosin Ariyo

May 2017

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Keywords: HPV Vaccine, Cervical cancer, Prevention, Rural Appalachia, Mother-Daughter, Socioecological context

ABSTRACT

Correlates of Human Papillomavirus (HPV) Vaccine Acceptance in Appalachian Tennessee

by

Oluwatosin Ariyo

Human papillomavirus (HPV) is the most prevalent sexually transmitted infection in the U.S., where one HPV-related cancer is diagnosed every 20 minutes. The most common HPV-related cancer is cervical cancer, with an estimated incidence of 12,000 cases annually, a third of which lead to death. Cervical cancer disparately affects women of ethnic minority groups and geographically isolated regions, such as Appalachia. Tennessee ranks third highest in cervical cancer incidence in the country. Many cases of cervical cancer could be prevented through vaccination against HPV, however, vaccination rates for females in Tennessee are among the lowest in the country. This mixed-methods study included an in-depth exploration of the factors that influence HPV vaccine acceptance in Appalachian Tennessee.

Healthcare providers, mothers of adolescent girls, and college-aged women were recruited to participate in the study. From October 2016 to January 2017, interviews were conducted with healthcare providers (n=12), focus groups were conducted with mothers (n=13), and a survey was administered to college women (n=479). Interview and focus group sessions were recorded, transcribed and analyzed using a thematic framework. Survey responses were analyzed using descriptive tests, comparison of means, and regression analyses.

The predominant barriers to vaccine acceptance identified in the study were: cost and novelty of the vaccine, vaccine safety, lack of school-entry requirement, and the implication of vaccine acceptance on adolescents' sexual activity. Most negative perceptions towards the vaccine

appeared to be propagated by the sociocultural influence on sex and reproductive health communication within the community. Perceived benefits for cancer prevention and receipt of strong and personal provider recommendations facilitated vaccine acceptance. Additionally, college students who reported vaccine acceptance reported discussing sexual health topics with their mothers more often than those who had not been vaccinated.

The findings from this study provide foundational insights about the facilitators and barriers of HPV vaccine acceptance in Appalachian Tennessee. Identifying and understanding these factors is crucial to improving HPV vaccination rates and essential to maximizing the primary benefit of the vaccine in addressing the existing cervical cancer disparity in the region.

DEDICATION

To my parents, for their unconditional love and selfless support. Especially to my mother for being the better half of our mother-daughter pair. I love you!

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CHAPTER 1

INTRODUCTION

Background of the Study

Human Papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the U.S. (CDC-Centers For Disease Control and Prevention, 2014). About 25% of the current U.S. population are currently infected with HPV, with an estimated 14 million new cases occurring each year (CDC-Centers For Disease Control and Prevention, 2014). HPV is so widespread that nine out of ten people will be infected in their lifetime (CDC-Centers For Disease Control and Prevention, 2014; National Cancer Institute, 2016). Of the 200 types of HPV, over 40 are sexually transmitted and can be categorized as either low or high risk (CDC-Centers For Disease Control and Prevention, 2014; National Cancer Institute, 2016; Vamos, McDermott, & Daley, 2008). The low-risk HPV types cause skin warts around the genitals, mouth, throat, and anus, while the high-risk types can cause cancer and account for over half of HPV infections (National Cancer Institute, 2016). Every 20 minutes, one HPV-related cancer is diagnosed in the U.S., the most common of which is cervical cancer (CDC-Centers For Disease Control and Prevention, 2014). Women between the ages of 20 and 24 years have the highest prevalence (45%) with incidence increasing with age, particularly between the ages of 14 to 24 years old (American Cancer Society, 2017; National Cancer Institute, 2016; Vanderpool, Casey, & Crosby, 2011). Cervical cancer is the third most common gynecologic cancer and the second leading cause of cancer mortality in young women between the ages of 20 and 39 years old (CDC-Centers For Disease Control and Prevention, 2017).

With the development of the HPV vaccine, these viral infections can be prevented. The effectiveness of the vaccine is optimized when received by adolescents before their first sexual

encounter (Brewer et al., 2013; CDC-Centers For Disease Control and Prevention, 2014; National Cancer Institute, 2016; Smith et al., 2013). Although the vaccine has proven to be almost 100% effective in preventing the development of cancerous cells in the cervix, low vaccination rates among adolescent women in the U.S. are still a public health concern (Brewer et al., 2013). These low vaccination rates are of particular concern among underserved populations such as Appalachian women, who experience a disproportionate burden of HPV-related cancers and high cervical cancer incidence and mortality (Blackley, Behringer, & Zheng, 2012; Brewer et al., 2013; Casey, Crosby, Vanderpool, Dignan, & Bates, 2013; Reiter, Fisher, et al., 2013; Reiter, Katz, & Paskett, 2012).

Some of the barriers that impede vaccine acceptance among underserved populations such as cost of the vaccine, lack of insurance, limited access to health services, and limited knowledge about HPV and the vaccine are often associated with low socioeconomic status and rurality (Holman et al., 2014). Individuals with low educational attainment often have low health literacy levels and low income levels, which further encumber their capacity to afford health services. In addition, residents of rural communities have limited access to health care facilities.

Previous studies have demonstrated that mothers play a significant role in maintaining the health of their family (Krieger et al., 2013; Roberts, Gerrard, Reimer, & Gibbons, 2010). The role of mothers is especially relevant in the uptake of vaccinations among adolescents, as maternal influence and endorsement have been shown to be predictors of young women's decision to receive the HPV vaccine (Krieger, Kam, Katz, & Roberto, 2011; Roberts et al., 2010). Among Appalachian women, this decision to receive the HPV vaccine is further influenced by factors within their social, cultural and economic environments (Brewer et al.,

2013; Casey et al., 2013; Head & Cohen, 2012; Hutson, Dorgan, Duvall, & Garrett, 2011b; Mills, Head, & Vanderpool, 2013; Vanderpool et al., 2011).

Purpose of the Study

Low HPV vaccination rates among young women in the Central and South Central Appalachian regions of the U.S., also referred to as rural Appalachia, place them at an increased risk for HPV and cervical cancer. While affordability of the vaccine is often cited as a barrier for low-income populations, such as those in rural Appalachia, studies have shown that even when cost is controlled for, vaccine uptake is still low in these regions (Crosby, Casey, Vanderpool, Collins, & Moore, 2011; Vanderpool et al., 2011). This phenomenon suggests the influence of other factors within the socio-ecological system. Studies have been conducted in Appalachian Ohio (North Central Appalachia) and Kentucky (Central Appalachia) in order to identify these factors, but only a limited body of knowledge investigating similar factors exists in Tennessee (Central and South Central Appalachia). Appalachian sub-regions are often categorized based on cultural and socioeconomic differences (Reiter et al., 2012), therefore it is important to identify and understand the specific barriers and predictors of HPV vaccine acceptance within each sub-region.

This study is an in-depth exploration of the broader context within Appalachian Tennessee, with the primary objective to gain an understanding of the underlying themes that influence HPV vaccine acceptance. In addition to the low social and economic status (education, income, availability of health services) often associated with geographically isolated areas, health status and outcomes among women in rural Appalachian regions are also predicted by cultural values. These values are often exhibited in interpersonal networks, with mothers as the primary influencers within these networks (Hutson, Dorgan, Duvall, & Garrett, 2011a; Hutson,

Dorgan, Phillips, & Behringer, 2007a). Considering these regionally-specific factors and the role of mothers in their daughters' health, it is pertinent to assess the correlation of sociocultural factors and mother-daughter communication with HPV vaccine acceptance in rural Appalachia. Additionally, since mothers often depend on recommendations from healthcare providers, and provider recommendation in Appalachia is lower than in non-Appalachian regions, it is important to understand the factors that drive provider attitudes towards vaccine recommendation.

While some studies have investigated HPV vaccination rates in Appalachia compared to their non-Appalachian counterparts (Kahn et al., 2007; Krieger, Katz, Kam, & Roberto, 2012; Roberto, Krieger, Katz, Goei, & Jain, 2011), fewer studies have explored the factors that influence vaccine acceptance within a multi-sectoral context. Likewise, some studies have investigated the role of mother-daughter communication in vaccine acceptance (Krieger et al., 2011; Roberts et al., 2010), but none have examined this relationship among mothers and daughters in rural Appalachia. Therefore, the purpose of this study is to utilize a conceptual framework that accounts for the impact of factors across the healthcare system, interpersonal networks, and sociocultural context on vaccine attitudes and behaviors in rural Appalachia.

Conceptual Frameworks Guiding the Study

A multi-sectoral systems model provides a conceptual framework to depict the systemic interactions of various factors that influence HPV vaccine uptake within the healthcare system, family context and community culture (Figure 1). Within the healthcare system, vaccine uptake is influenced by a provider's recommendation, which is largely influenced by the provider's attitudes and beliefs towards the vaccine (Gilkey & Mcree, 2016; Kahn et al., 2007; Krieger et al., 2012; Roberto et al., 2011). A provider with ambivalent or negative attitudes towards the

HPV vaccine is less likely to recommend it to patients, or could directly discourage it. The community culture in which a provider practices also has a major effect on their attitudes and beliefs. Healthcare providers who practice in communities where the HPV vaccine is equated with promiscuity are more likely to have negative attitudes towards the vaccine or anticipate negative reactions from parents, and are thus less likely to recommend the vaccine (Krieger et al., 2012). Low provider recommendation further perpetuates low levels of awareness and negative attitudes about the vaccine within the community context, propagating the notion that, if a health professional has concerns about the vaccine, these ‘expert-based concerns’ must be valid and should be heeded.

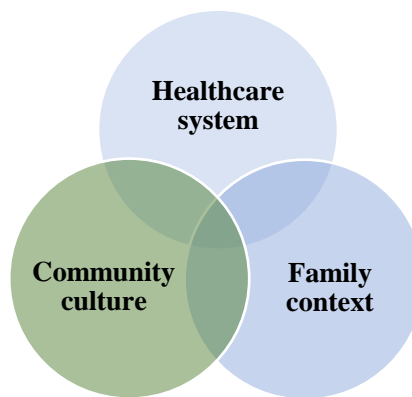


Figure 1: Model of Multi-Sectorial Systems Thinking

Within the family context, a parent’s or a young woman’s decision to receive the vaccine is influenced by their socioeconomic status, attitudes and beliefs about HPV, the vaccine and cervical cancer, and ultimately by interpersonal relationships (Hutson et al., 2011a; Mills et al., 2013; Vanderpool, Dressler, Stradtman, & Crosby, 2015). Her literacy levels and ability to access health information influence a mother’s knowledge about the vaccine. Her attitudes towards the vaccine are, in turn, influenced by norms and cultural values, and her ability to

receive the vaccine is influenced by her income and access to health services (Katz et al., n.d.; Reiter, Katz, & Paskett, 2013).

Within each of these sectors, the individual-level factors that facilitate or inhibit HPV vaccine acceptance can be further assessed using the Integrated Behavior Model (IBM). The IBM provides a theoretical framework to describe individuals' perceptions and attitudes that predict their intentions to receive or recommend the HPV vaccine. This model is derived from overlapping constructs contained in five prominent theories of health behavior (Theory of Reasoned Action, Theory of Planned Behavior, Social Cognitive Theory, Theory of Interpersonal behavior, and the Health Belief Model). The IBM offers relevant constructs which are crucial precursors to preventive health behaviors like HPV vaccine uptake (Head & Cohen, 2012; Montaña & Kasprzyk, 2008). These constructs include: attitudes, beliefs, knowledge, norms, personal agency, environmental constraints and intention (Figure 2). For instance, knowledge, awareness and normative influences concerning HPV would shape a mother's beliefs about the vaccine and subsequently impact her intention to accept the vaccine for her daughter. Similarly, these constructs would influence a young woman's intention for receipt, and a healthcare provider's intention to recommend the vaccine (Head & Cohen, 2012). The IBM model also provides a conceptual framework to depict how an individual's attitudes and beliefs about receiving/recommending the HPV vaccine are influenced by knowledge and awareness about the virus and the vaccine, the effect of normative influences within their interpersonal networks (defined as endorsement of the vaccine by significant figures in a woman's life), and environmental factors within the community context which further facilitate or impede vaccine uptake. These constructs are depicted in figure 2 below, boxes in bold represent constructs that will be assessed in the study aims.

In accordance with the purpose of the study, the multi-sectoral and IBM models provide the theoretical foundation to explore individual-level factors within the healthcare system, family context and community culture, associated with HPV vaccine acceptance in rural Appalachia, develop measures to test these factors, and identify overlapping factors across each sector. Additionally, the models serve as a vehicle to identify leverage points for action and serve as a framework to develop culturally-relevant, evidence-based programs to eliminate identified barriers associated with the HPV vaccine.

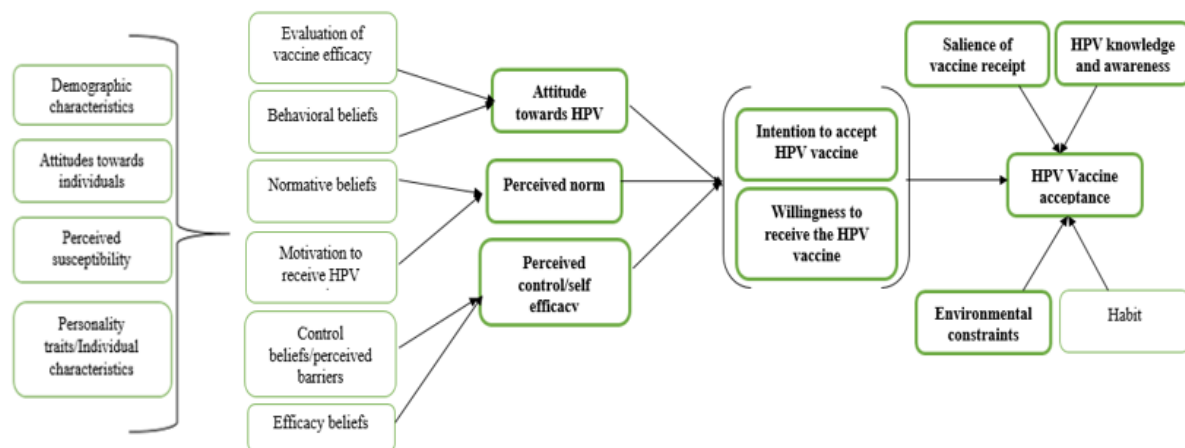


Figure 2: Integrated Behavior Model Depicting Factors That Influence HPV Vaccine Acceptance

Research Aims

This study aims to add to the body of knowledge about factors associated with sub-optimal HPV vaccination rates among rural Appalachian women. Considering the disparate burden of cervical and other HPV-related cancers in most of rural Appalachia, and the existence of a primary prevention tool in the HPV vaccine to address this health problem, it is of particular concern that the vaccine is not readily accepted among this high-risk population. Therefore, this study seeks to explore the underlying factors of low vaccine uptake among women in Appalachian Tennessee.

Healthcare providers, mothers and young women are the primary actors in the conversation around HPV vaccine acceptance and uptake. Parents, adolescents and providers are influenced by their mutual interactions with each other; effective communication among this triad has been shown to positively influence vaccine acceptability and increase uptake (Hughes, Jones, Feemster, & Fiks, 2011). Adolescents are primarily dependent on their mother's endorsement and support of the vaccine, as well as their provider's recommendation, to initiate vaccine uptake. Mothers, in turn, are also influenced by clinician's recommendation and social norms within their interpersonal networks. Clinicians are influenced by normative influences within their practice and their community context. Based on this evidence, it is important to elicit a comprehensive understanding of factors that influence HPV vaccine acceptance among women and providers in Appalachian Tennessee.

The knowledge gained from this study can be applied to increase vaccination rates and would substantially aid in preventing cervical cancer among this population with a disparate burden of cervical cancer (Reiter, Fisher, et al., 2013). To achieve this overarching goal, the specific aims of this study are to:

Research Aim I

Explore HPV vaccine-related attitudes and perceptions among a sample of healthcare providers within Appalachian Tennessee.

Research Aim II

Explore attitudes, perceptions, knowledge and awareness related to the HPV vaccine among Appalachian mothers.

Research Aim III

Measure vaccination rates and assess attitudes, perceptions, knowledge and awareness related to the HPV vaccine among a sample of young women who fall within the recommended age range (≤ 26 years) for vaccine dose completion.

Research Aim IV

Explore associations between mother-daughter sexual health communication and vaccine acceptance in Appalachian Tennessee.

CHAPTER 2

LITERATURE REVIEW

Human Papillomavirus

Etiology and transmission. Human papillomaviruses (HPVs) are a group of wide and diverse viruses (Bzhalava, Guan, Franceschi, Dillner, & Clifford, 2013). Each virus in the group is characterized by a number, which is called an HPV type. There are almost 200 identified HPV types, with continuous discovery of new types (Bzhalava et al., 2013). These viruses adapt to the tissues of their host and commandeer the human cellular mechanism for their viral replication and maintenance (Muñoz, Castellsagué, de González, & Gissmann, 2006). An HPV infection begins when the virus enters the basal layer of the epithelium through cuts or abrasions in the skin, and then proliferates throughout the infected region, destroying healthy host cells in the process (Muñoz et al., 2006). The virus is primarily transmitted through dermal contact and can be contracted through vaginal, oral or anal sex. HPV can be transmitted from infected persons who are symptomatic or asymptomatic (CDC-Centers For Disease Control and Prevention, 2014).

Epidemiology. HPV is a very common infection and is the most prevalent STI in the U.S. with about 25% of the U.S population currently infected and an estimated 5% new cases diagnosed every year (CDC-Centers For Disease Control and Prevention, 2014). All sexually active males and females can get HPV, and most will be infected at some point in their lives (CDC-Centers For Disease Control and Prevention, 2014). The prevalence of HPV in the U.S. is highest among young women, with increasing prevalence between the ages of 14 to 24 years, peak prevalence below 25 years, decreasing prevalence between ages 35 to 54 years, and a second peak after 55 years (Baseman & Koutsky, 2005; Roberts et al., 2010; Vanderpool et al.,

2011). HPV prevalence in women over the age of 30 is mostly due to persistent infections (Baseman & Koutsky, 2005). The incidence of HPV is highest among sexually active young adults with increasing incidence soon after sexual debut.

Number of sexual partners is the primary risk factor for HPV infection (American Cancer Society, 2016; Baseman & Koutsky, 2005; CDC-Centers For Disease Control and Prevention, 2014). Studies have shown a strong positive association between lifetime number of sexual partners and HPV infection in both males and females. Studies have also shown that HPV infection in a woman is positively associated with the number of her male partner's lifetime sexual encounters, with increased incidence among women whose partners have multiple partners. Uncircumcised males have a higher risk for HPV infection, as do their female partners. Other factors that may be associated with increased risk of HPV infection are suppressed immunity (either due to disease or drugs that weaken the immune system) and smoking (Baseman & Koutsky, 2005).

HPV-Related Diseases. HPVs are responsible for a number of diseases ranging from benign lesions to malignant tumors. Each HPV type is further classified into groups depending on which membrane of the skin it often infects and the type of disease associated with the subsequent infection. Those that infect the moist surface layers that line organs and cavities in the human body are called *mucosal HPV* types, and those that infect the skin are called *cutaneous HPV* types (American Cancer Society, 2016; Bzhalava et al., 2013). Approximately 75% of identified HPV types are cutaneous, and about 25% are mucosal. These groups are further subdivided into *oncogenic low-risk* and *oncogenic high-risk* (American Cancer Society, 2016). The cutaneous types are often oncogenic low-risk and usually cause skin warts around the hands and feet (American Cancer Society, 2016). Some high-risk cutaneous types have also been

found in non-melanoma skin cancers (NMSCs) such as basal and squamous cell carcinoma (Bzhalava et al., 2013). The mucosal types, also known as (ano)genital types because they are often found in the anal or genital regions, can either be high-risk or low-risk (American Cancer Society, 2016). The low-risk types (HPV 6 & 11) often lead to genital warts, while the high-risk types (e.g. HPV 16 & 18) can lead to cancers of the cervix, vulva, anus, vagina, penis, throat, tongue and tonsils (American Cancer Society, 2016; Bzhalava et al., 2013). Cervical cancer is the most common HPV-related cancer (CDC-Centers For Disease Control and Prevention, 2014). The International Agency for Research on Cancer (IARC) recently classified 12 mucosal types (HPV 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58 and 59) as 'high-risk' due to their association with cervical cancer (Bzhalava et al., 2013; International Agency for Research on Cancer, 2012).

Cervical Cancer

Etiology. Strong epidemiological evidence has established the role of HPV in cervical cancer incidence; HPV is a primary and necessary cause of cervical cancer (Crosbie, Einstein, Franceschi, & Kitchener, 2013; Muñoz et al., 2006). A woman must be infected with HPV to develop cervical cancer. While this infection could be from any of the high-risk types, about 75% of cervical cancer cases are caused by HPV16 or 18. HPV infections can be asymptomatic and may clear without treatment. However, sometimes the infection persists and leads to the formation of pre-cancerous cells (American Cancer Society, 2014). Not all pre-cancerous cells become invasive cancers, but progression is unpredictable and could develop in a space of a few months or years (American Cancer Society, 2014). There are four major steps in the development of cervical cancer: HPV infection of the epithelial layer, viral persistence, progression of persistent infections to pre-cancerous cells, and invasion of the epithelial

membranes (Schiffman, Castle, Jeronimo, Rodriguez, & Wacholder, 2007). Once HPV begins proliferation in the epithelial layers, it causes the production of two proteins (E6 and E7) which inactivate tumor suppressor genes (American Cancer Society, 2014; Muñoz et al., 2006). This process promotes accelerated growth of epithelial cells lining the cervix thus causing pre-cancerous cell transformation (Muñoz et al., 2006).

Epidemiology. Cervical cancer is the third most commonly diagnosed gynecologic cancer in the U.S. and the second leading cause of cancer mortality in women between the ages of 20 to 39 years old (Rauh-Hain et al., 2013) The current incidence rate of cervical cancer in the U.S. is 7.7/100,000 women, which translated to an estimated 12,990 new cases and 4,120 deaths in 2016 (American Cancer Society, 2017). The estimated mortality from cervical cancer (31.7%) in the U.S is almost double that of breast cancer (16.3%). Cervical cancer is more prevalent among women in their middle ages, and rarer in women older than 50 years, although more than 15% of cervical cancer cases occur in women over 65 years who have not being regularly screened (American Cancer Society, 2014).

Established risk factors that are associated with cervical cancer incidence are: smoking, long term use of oral contraceptives, high number of full-term pregnancies, poverty and immunosuppression (American Cancer Society, 2014; Muñoz et al., 2006). Women who smoke are almost twice as likely to develop cervical cancer compared to non-smokers. Tobacco molecules have been found in the cervical mucus of smokers (American Cancer Society, 2014). Based on this evidence, researchers suggest that tobacco damages the DNA of cervical cells thus contributing to the development of cancer (American Cancer Society, 2014). Additionally, smoking compromises the immunity of smokers making their immune systems less effective in clearing HPV infections (American Cancer Society, 2014). Findings from a meta-analysis which

reviewed the association between cervical cancer and oral contraceptives (OC) show an increased risk of cancer with increased duration of OC use (Muñoz et al., 2006). The results of the analysis indicated that women with ten years use of OC were twice as likely to develop cervical cancer compared to those who had never used OCs (American Cancer Society, 2014; Muñoz et al., 2006). The hypothesized route through which OCs increase risk is interactions between the hormones and the hormone-receptors in the viral genome (American Cancer Society, 2014; Muñoz et al., 2006). As a result of disruption of the cervical cells during pregnancy and child birth, and hormonal interactions, women with a high number of full-term pregnancies may have an increased exposure to HPV (American Cancer Society, 2014; Muñoz et al., 2006). Women with suppressed immune systems such as those with AIDS, or those taking drugs to suppress their immunity, have less capability to fight off HPV infections and are thus at higher risk for cervical cancer (American Cancer Society, 2014). Poverty is also associated with increased risk, as women of low income are less likely to be able to afford and access preventive services (American Cancer Society, 2014). Other factors that have shown some association with increased risk for cervical cancer incidence are: chlamydia infection, obesity, diet and nutrition, and previous family history of cervical cancer (Pierce Campbell, Menezes, Paskett, & Giuliano, 2012; US Preventive Services Task Force, 2012).

Prevention. Primary prevention of cervical cancer can be achieved by avoiding exposure to HPV and/or preventing HPV infection through receipt of the HPV vaccine (American Cancer Society, 2014; CDC-Centers For Disease Control and Prevention, 2014) Progression of pre-cancerous cells to invasive tumor can also be prevented through regular screening and early detection. The U.S. Preventive Services Task Force (USPSTF) recommends that women between the ages of 21 and 65 years receive a pap smear every three years and that women between the

ages of 30 and 65 years receive HPV testing every five years (US Preventive Services Task Force, 2012).

Disparities. Since the development and promotion of pap tests and other secondary preventive measures (HPV vaccine and testing), rates of cervical cancer incidence and prevalence across the country have declined by more than 75% (Pierce Campbell et al., 2012). However, this decline has not been equally observed across all populations, and disparities in incidence and mortality persist across certain racial/ethnic groups and geographic regions (Pierce Campbell et al., 2012; Rauh-Hain et al., 2013). Over 60% of cervical cancer cases occur among women of disadvantaged communities (Pierce Campbell et al., 2012). Recent cancer surveillance data show that the age-adjusted incidence rate is highest among Hispanic women (9.2/100,000), followed by Black women (9.0/100,000), compared to the average rate of 7.2/100,000 persons (CDC-Centers For Disease Control and Prevention, 2017). Mortality rates¹ also show similar patterns, with highest rates amongst Black (3.9/100,000) and Hispanic women (2.5/100,000) (CDC-Centers For Disease Control and Prevention, 2017).

Regional disparities in cervical cancer incidence and mortality also exist across the country. Women in communities along the U.S.-Mexico border, in the Southern parts of the U.S. and in the Appalachian region have disproportionately higher diagnostic and death rates (Pierce Campbell et al., 2012). Surveillance data indicate that white women living in Appalachian regions have higher rates than white women in non-Appalachian regions (Pierce Campbell et al., 2012; Reiter, Fisher, et al., 2013; Reiter et al., 2012). Data from 2008 showed that seven out of 13 Appalachian regions had higher mortality rates than the national average, six of the seven of

¹ Corrected age-adjusted mortality rate was 10.1/100,000 for black women and 4.7/100,000 for white women (without regard for Hispanic ethnicity) (Beavis, Gravitt, & Rositch, 2017).

which are Southern Appalachian sub-regions (Blackley et al., 2012). This disparity also exists by state, with a majority of Southern states experiencing higher incidence and mortality than the national rates. One such state is Tennessee with an age-adjusted incidence rate of 8.9/100,000 women compared to a national average of 7.2 and an age-adjusted mortality rate of 2.8/100,000 women compared to the average rate of 2.3/100,000 women (CDC-Centers For Disease Control and Prevention, 2017).

Appalachia

In 1965, federal legislation officially designated the Appalachian regions, with subsequent counties added through the years. Currently, Appalachia is a 13-state, 420-county region that spans across 200,000 square miles from southern New York through northern Mississippi (Blackley et al., 2012; Reiter et al., 2012) (Figure 3). With an estimated population of 25 million, the region makes up about 8% of the U.S. population and about one-quarter of the total population of the 13 states.

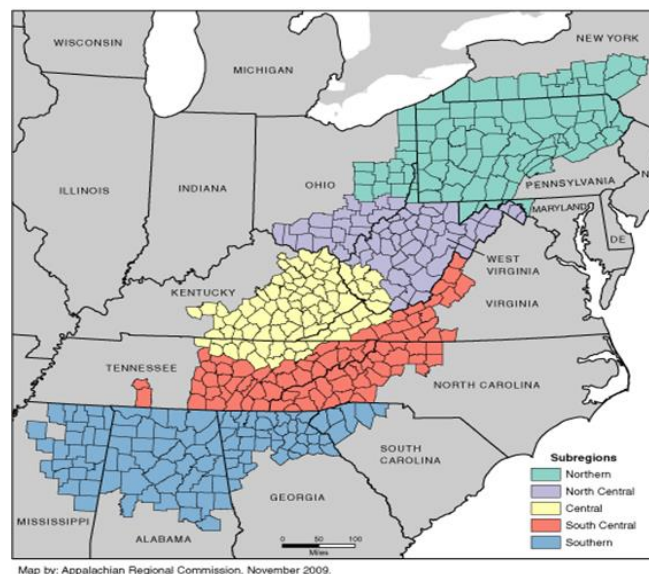


Figure 3: Map of the Appalachian Region. Reprinted from Maps- Appalachian Regional Commission. Retrieved February 2017 from <https://www.arc.gov/maps>. Copyright 2017 by The Appalachian Regional Commission. Reprinted with permission

Rurality. Over a third of Appalachian counties are classified as rural, in that they are characterized by low population density, geographic isolation and having low economic resources (Behringer & Friedell, 2006). Rural areas across the country and within the region are often correlated with high poverty rates, low educational attainment, and low income (Behringer & Friedell, 2006; Blackley et al., 2012). Based on geographic isolation and limited resources, rural areas such as those in Appalachia, also have sparse health infrastructure and health care facilities and limited accessibility to facilities in urban areas.

Education. Evidence indicates the existence of an inverse relationship between educational attainment and health outcomes; the lower the education level, the higher the likelihood of negative health outcomes (Robert Wood Johnson Foundation, 2009). The Appalachian region has historically achieved lower than average high school graduation rates (Appalachian Regional Commission, 2014). Lower educational attainment is correlated with higher unemployment, lower income and low literacy levels (Robert Wood Johnson Foundation, 2009).

Income. The association between lower income and negative health status is so evident that poverty has been termed a ‘carcinogen’ (Brodish, Massing, & Tyroler, 2000; Ward et al., 2004). Low income individuals face issues of healthcare affordability, insufficient health insurance coverage, and lower accessibility to health care information and resources, and as such, are more likely to engage in unhealthy behavior and less likely to utilize preventive services (Behringer & Friedell, 2006; Blackley et al., 2012; Hopenhayn, King, Christian, Huang, & Christian, 2008). Appalachian poverty rates are about 11% higher than the national average (Appalachian Regional Commission, 2014).

Economic Status Designation. Using an index-based county classification system, the Appalachian Regional Commission (ARC) identifies and monitors the economic status of counties within the region. This system compares each county's economic indicators (3-year average unemployment rate, average income and poverty rate) with the national averages, and then ranks them based on the aggregate index (Appalachian Regional Commission, 2014).

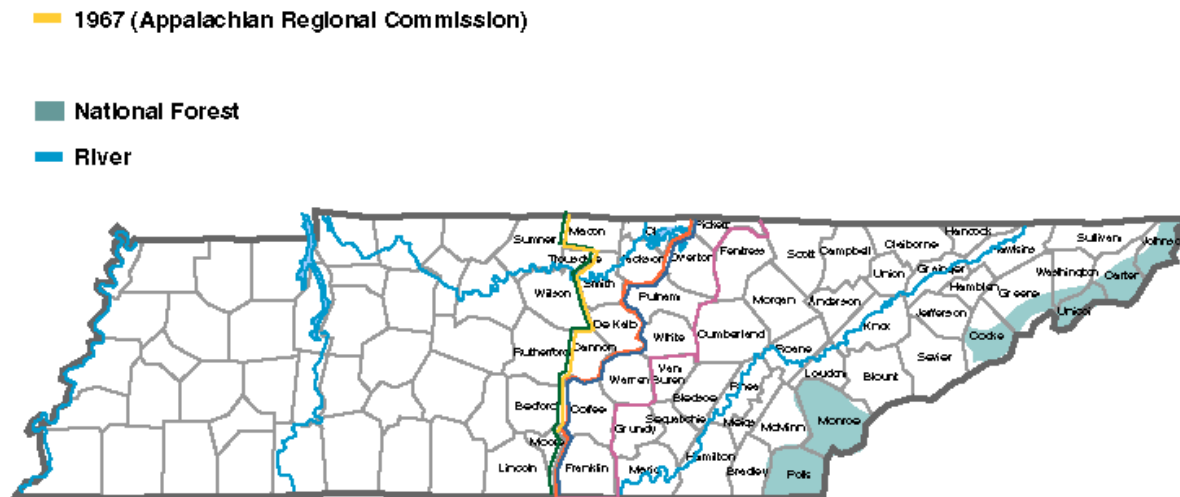


Figure 4: Map of Counties in Appalachian Tennessee. Map of the Appalachian Region. Reprinted from Maps- Appalachian Regional Commission. Retrieved February 2017 from <https://www.arc.gov/maps>. Copyright 2017 by The Appalachian Regional Commission. Reprinted with permission.

There are five existing designations for economic status: Distressed (counties with at least two times the national poverty rate and average unemployment rate, and per capita income at 67% of the national average), At risk (counties with at least 125% unemployment and poverty rates, and per capita income of at most 67% of national average), Transitional (counties that have worse status than the national average but do not meet criteria for ‘at-risk’ or ‘distressed’ designations), Competitive (counties with unemployment and poverty rates that are at least equal to the national average, and per capita income of 80% or more than the national average), and Attainment (counties with economic indicators that are at least equal to the national average) (Appalachian Regional Commission, 2014). Only six Appalachian counties have reached the

attainment status. Counties in Tennessee fall within either of the distressed, at-risk, or transitional status.

Cultural Identity. Appalachia possesses a distinct cultural identity with family as the soul of the community and a key source of information (Blackley et al., 2012; Hutson et al., 2011b; Krieger et al., 2013). A large proportion of the region comprises the ‘Bible-belt’ which consists of some of the most religious and politically conservative groups in the country (Reiter et al., 2012). Within the family and community structure, there are deep-rooted perceptions of gender roles with females assuming major responsibility as caretakers of the family, often placing this role as a higher priority over caring for themselves (Blackley et al., 2012; Krieger et al., 2013). Some studies also report residents’ objection to the term ‘Appalachia,’ indicating that it denotes a derogatory and negative stereotype to their actual attitudes and beliefs (Behringer & Friedell, 2006; Hutson et al., 2011b).

HPV-Cancer Burden in Appalachia. Based on the low socioeconomic profile and geographic isolation of rural Appalachia, many women in the region experience low literacy, low income, and inaccessibility to health services that predispose them to negative health status and outcomes. This issue is evident in the disproportionate burden of cervical and other HPV-related cancers. Reiter et al. (2013) conducted a study to assess the prevalence of HPV-related cancers in three Appalachian regions (Kentucky, Ohio and West Virginia) and found that the age-adjusted incidence of HPV-related cancers was higher in the Appalachian regions of these states compared to their non-Appalachian counterparts (Reiter, Fisher, et al., 2013). These findings strongly suggest that preventing HPV infections among this population is a priority for public health.

HPV Vaccine

To address the burden of HPV-related diseases and cancers, three vaccines have been licensed and recommended for routine vaccination. In 2006, the U.S Food and Drug Administration (FDA) licensed the first prophylactic HPV vaccine. This quadrivalent vaccine, Gardasil (Merck & Co., Inc.), prevents against four types of anogenital HPV: 6, 11, 16 and 18, which are established causal factors for genital warts and cervical cancers. In 2009, a bivalent vaccine, Cervarix, was developed by GlaxoSmithKline to protect against HPV16 and 18. Most recently, in 2014, a 9-valent vaccine was licensed to prevent against the four types covered by the quadrivalent vaccine and five additional types: HPV31, 33, 45, 52, and 58 (CDC-Centers For Disease Control and Prevention, 2015). These vaccines protect against 7 out of 12 of the HPV types classified by IARC as carcinogens (Bzhalava et al., 2013; International Agency for Research on Cancer, 2012).

The Advisory Committee on Immunization Practices (ACIP) recommends routine HPV vaccination for males and females beginning at 11 or 12 years. The 3-dose² vaccine series can be started at age 9 and should be completed either one or two, and six months after the first dose. The vaccine can also be received by females between the ages of 13 and 26 who have not started or completed their dose, and by males through the age of 21. The vaccines have close to 100% effectiveness in preventing against their associated HPV types when received before sexual initiation and exposure to the virus (CDC-Centers For Disease Control and Prevention, 2015; Saslow et al., 2007). The vaccines have also shown no evidence of adverse effects in clinical

² Recent updates in ACIP recommendations: For persons initiating vaccination before their 15th birthday, the recommended immunization schedule is 2 doses of HPV vaccine. The second dose should be administered 6–12 months after the first dose (Meites, Kempe, & Markowitz, 2016).

trials to evaluate safety (CDC-Centers For Disease Control and Prevention, 2015; Saslow et al., 2007).

The earliest age recommended for vaccine initiation is 9 years old. This is largely because it represents the lowest age limit for inclusion in clinical trials, and as such, the vaccine could not be tested among younger age groups. The recommended age for vaccination is particularly important as vaccine effectiveness is optimized if administered before sexual initiation or shortly after. Based on the prophylactic nature of the vaccine, risk of infection was estimated using adolescents' age at sexual initiation (Saslow et al., 2007). According to nationally-representative survey data, 1 out of 4 females in the U.S. reports being sexually active by 15 years, 4 out of 10 by age 16, and 7 out of 10 by age 18 (Saslow et al., 2007). Risk of infection is also estimated based on probability of exposure because HPV infection occurs within a few years of sexual initiation. One study of college-aged women found that 39% of the study participants had an HPV infection within 2 years of sexual engagement, and another study of adolescents (13-21 years) showed that 70% of participants had an infection within 5-7 years from sexual initiation (Saslow et al., 2007).

Barriers to prevention . Despite the evident necessity and effectiveness of the HPV vaccine, vaccination rates across the country remain sub-optimal, especially among populations at highest risk for cervical cancer (Holman et al., 2014; Reiter et al., 2012). This suggests that there are factors that impede access to and/or acceptability of the vaccine. Research indicates that challenges within the healthcare system and personal and social attitudes about health are potential barriers to vaccine uptake among women and girls in Appalachia.

A systematic review on barriers to HPV vaccination among U.S. adolescents found that health care professionals often cited parental financial constraints and attitudes towards the

vaccine as barriers to recommending and providing the vaccine. Parents cited low knowledge and awareness, concerns that giving the vaccine was license for promiscuity, low perceived risk for adolescent's HPV infection, and perception of vaccine disapproval within their social circles as barriers to prevention (Holman et al., 2014). A review of the National Immunization Teen survey data (NIS-teen) reviewing barriers and intentions for vaccination in Appalachian regions found that parents were resistant to the HPV vaccine for a variety of reasons. A number of parents felt that the recommended age for vaccination was too young, some felt that the vaccine was not relevant for their daughter, others cited their daughters' sexually naïveté as reason for vaccine irrelevance (Reiter, Katz, et al., 2013). Parents whose healthcare providers had not recommended or had discouraged the vaccine were also more resistant to the vaccine. Additionally, some parents reported low awareness and knowledge about HPV and the vaccine, and concern about the cost of the vaccine as barriers to accepting the vaccine for their daughters (Reiter, Katz, et al., 2013).

A qualitative study among providers, parents, community leaders and adolescents in Appalachian Ohio revealed similar themes (Katz et al., n.d.). Within the healthcare system, cost of the vaccine, low access to healthcare, lack of health insurance, and poor provider-patient communication were cited as barriers to vaccine uptake. From an individual perspective, fear of short- and long-term side effects that would affect fertility, cause other illness, or increase promiscuity were indicated as barriers, as were low knowledge and awareness. Within the social and cultural context, fear that vaccine uptake could lead to judgment and gossip, and perceived conflict of the vaccine's objectives with religious beliefs were cited as additional barriers. These cultural barriers were corroborated by findings from another study that investigated communication barriers within the Appalachian culture and found that advertising skepticism

and fear of reproductive health side effects were common barriers to vaccine uptake (Hutson et al., 2011b).

Communication, Culture, and Health

Culture is the multidimensional, ecological system in which a community exists, and consists of a collection of beliefs and values shaped by varying responses to the social, geographic, political and religious environments. Cultural values, in turn, shape a community's attitudes towards health, health behaviors, and the concept of cancer (Kagawa-Singer, Dadia, Yu, & Surbone, 2010). While the concept of culture is often applied to immigrant and ethnic groups, it is important to note that every community has an underlying theme through which they view and interpret their daily experiences. While many studies on health disparities have established the role of social and economic determinants of health (e.g., education, income, geography, etc.), the role of culture is often overlooked. At the core of every community is this salient determinant of health that influences how we interpret health practices, determines the social structures within families, and provides a blueprint for community relations.

Scholars suggest that the core of the rural Appalachian culture is rooted in the distinctive interaction between geographic isolation and economic depravity which may have led families and communities to exclusively depend on each other and form close knit ties (Hutson, Dorgan, Phillips, & Behringer, 2007b). The theory is that these ties have fostered a culture of storytelling through which issues, including information on health and wellness, are disseminated (Hutson et al., 2007b). As a result of this communication mechanism, negative individual perceptions about the healthcare system, health behavior, sexual health, and cancer in particular are often projected onto family members, individuals within their social networks and the larger community (Vanderpool et al., 2015). In the absence of any individual perceptions or experiences, little

information is disseminated and low levels of knowledge are perpetuated within the community (Hutson et al., 2011a, 2007b).

This communication culture is evidenced in the case of HPV and cervical cancer communication in rural Appalachia where healthcare providers often do not talk to their patients about HPV, the vaccine or cervical cancer (Hutson et al., 2011a; Krieger et al., 2012; Roberto et al., 2011). Thus, the foundational knowledge on these health issues is limited. Based on its associated stigma, sexual health issues are often not a topic of discussion within family and community networks. This limited dialogue on HPV and the vaccine has led to the perpetuation of ‘spheres of silence’ within rural Appalachian communities (Hutson et al., 2011a). However, the propagation of information from anti-vaccine messaging, which often cite vaccine side effects and the reasoning that it encourages promiscuity, is more likely to dominate an Appalachian woman’s perceptions and shape her attitudes towards the vaccine (Hutson et al., 2011a; Krieger et al., 2013).

Providers’ influence on HPV Vaccine Acceptance

Receiving a recommendation from a healthcare provider is an important predictor of HPV vaccine uptake (Kahn et al., 2007; Reiter, Katz, et al., 2013; Roberto et al., 2011). Providers both directly impact vaccine uptake, as their attitudes influence parental willingness to accept the vaccine for their daughters, and indirectly, as it determines the level and quality of available vaccine information within a rural community. It is therefore of particular concern that pediatricians in Appalachian regions are less likely to recommend the vaccine compared to their non-Appalachian counterparts. Reasons for low recommendation ranged from low perceived susceptibility of their patients to concern about negative parental attitudes due to social and cultural implication and cost of the vaccine (Kahn et al., 2007; Krieger et al., 2012). Despite

these findings, we do not have extensive knowledge on the factors that influence vaccine recommendation among a wider range of health care providers (i.e., nurse practitioners, primary care physicians, gynecologists, and pediatricians), particularly in rural Appalachia.

Maternal Influences

Mothers play a central role in the health of their families, especially in their daughter's health. Not only are girls more likely to communicate with their mothers than their fathers about their sexual health, but their personal attitudes towards the vaccine are also influenced by maternal endorsement (Roberto, Krieger, & Katz, 2014). This is also true in Appalachia where mothers are often the gatekeepers of the family's health and wellbeing and a key source of health information (Krieger et al., 2013).

Mothers are an important source of psychosocial (endorsement) and instrumental (financial) support in young women's vaccine uptake, and they serve as the primary decision-makers on adolescents' HPV vaccine receipt (Gilkey & Mcree, 2016; Krieger et al., 2011). Maternal endorsement of the vaccine, and willingness and ability to pay for the associated costs significantly impact their daughter's vaccine uptake (Krieger et al., 2011). Krieger et al. (2011) conducted a study among mother-daughter dyads in a Midwestern U.S. university and found that daughters who reported discussing the vaccine with their mothers were nine times more likely to have received the vaccine compared to those who had not. The results indicated that a mother's intention to encourage their daughters to talk to their physician about the vaccine was associated with the daughter's report of maternal HPV communication and receipt of the vaccine.

CHAPTER 3

METHODS

Introduction

The bulk of the proposed study methodology (design, participant recruitment, and measures) has been implemented in previous HPV vaccine studies among healthcare providers, mothers and adolescents. However, since most of these studies were conducted before widespread availability of the three vaccines and among different populations (not including rural Appalachia), the study elements were modified to suit the proposed aims of this study as well as the study population. Prior to data collection, all elements of the study were reviewed and approved by the university's institutional review board (IRB).

Design

This study utilized a mixed-methods approach to explore factors associated with HPV vaccine acceptance and self-reported vaccine uptake in Appalachian Tennessee. Semi-structured interviews and focus groups were conducted to gain in-depth views on important individual and contextual factors. These qualitative methods provided richer and deeper insights into the attitudes and beliefs associated with HPV vaccine acceptance. Quantitative methodologies were implemented to measure associations, frequencies and trends in vaccination status based on collated data from the completed surveys. Findings from both arms of the study were then triangulated to identify diverging and converging themes across the triad.

Study Setting and Participants

Semi-structured Interviews: Using a purposive sampling strategy to ensure adequate representation by gender, practice setting (clinic, hospital, academic-affiliated), and ARC

economic status designation of the county of practice (distressed, at-risk, transitional)³, healthcare providers were recruited from Washington, Sullivan, and Unicoi counties in Northeast Tennessee. The investigator identified prospective participants through her social and professional networks and by reviewing listed resources of health services information in these counties. To be eligible for the study, the interview participant had to be a healthcare provider, practicing in one of the aforementioned counties, and administering vaccines as part of their clinical practice. Recruitment letters (Appendix A) were sent by email to eligible healthcare providers, and then follow-up contacts were made by phone, if necessary. A total of 12 healthcare professionals were interviewed between November 2016 and January 2017 (Table 1). This sample of 12 healthcare professionals included three key informants who were initially interviewed to provide first-hand knowledge about health services in the community and to pilot test the proposed interview questions for comprehension and relevance. The remaining nine healthcare providers were then subsequently interviewed using the finalized question guide.

Focus Groups: A recruitment letter (Appendix B) was disseminated via email to faculty and staff at East Tennessee State University. Mothers with at least one daughter between the ages of 11 and 26 years were invited to participate in a focus group. This convenience sample provided access to eligible participants who potentially lived in diverse communities, reflective of different county ARC designations. To ensure that the study also included participants from more distant communities which may not be represented in the campus population, eligible mothers were also recruited from Hancock County, TN. Interested women who read the recruitment material completed an eligibility screener (Appendix C), read the consent document,

³ Since Appalachian Tennessee falls within Central and South-Central Appalachian which is classified as rural, it would be redundant to group counties using rural-urban continuum. Hence, the study will utilize ARC-economic status designation for county economic index classifications.

and signed up for a convenient time slot. Two focus groups (n=13) were conducted between November and December 2016 (Table 2).

Survey: The study employed a cross-sectional design to recruit a convenience sample of female students from East Tennessee State University. Students were recruited using the Department of Psychology's online research participation site (Sona systems), and eligibility was limited to female students who were at least 18 years old at the time of survey completion. All females regardless of vaccination status were eligible for study participation. The survey was administered over a 3-month period from October to December 2016.

Data Collection

Qualitative. During each scheduled interview session, participants signed informed consent documents (Appendix D) and completed a 6-item, paper-based questionnaire assessing demographic and practice characteristics (Appendix E). Using a semi-structured guide, the interview explored providers' perceptions of vaccine acceptance both from the patient and practice perspective and their attitudes towards the vaccine (Appendix F). The sessions were conducted at convenient and private locations, chosen by the providers (clinic office = 9, church office = 1, home = 1), with an average duration of 35 minutes. Provider participation was voluntary with no expected compensation.

Eligible women were invited to participate in a focus group to share their opinions and experiences with the HPV vaccine. The focus group with the campus participants was held at a central location on the university campus, conducted at lunchtime during the work week. During the scheduled session, participants signed informed consent documents (Appendix D) and completed a short survey assessing demographic characteristics, daughter's vaccination status, family history of cervical cancer, and vaccine recommendation from their healthcare provider

(Appendix G). The community session was held at the Hancock County Art Center and conducted in the evening after the work day. Each focus group session lasted approximately 60 minutes, and light meals were provided as compensation for participants' time. The interviews and focus group sessions were audio-recorded and then transcribed verbatim by a CITI-trained research assistant.

Quantitative. Prior to survey completion, participants were required to read and consent to study participation. The online surveys were completed outside of class periods, at any convenient time and place chosen by the participants, and lasted an average of 30 minutes. The questionnaire was administered through Survey Monkey, and the link to access the survey was made available through the Sona system. University students with access to the Sona system who met the inclusion criteria and completed the survey received course credit as compensation for their time. The survey started with a brief eligibility screener to determine gender and age and progressed with general demographic questions and constructs related to reproductive health and vaccine acceptance (Appendix I). A total of 479 valid responses were collected during the 3-month study period.

Measures

Research Aim I

To explore HPV vaccine attitudes and perceptions among a diverse sample of healthcare providers in Appalachian Tennessee.

The semi-structured interviews followed an open-ended question guide (Appendix F) and began with general questions about the provider's role in the practice, clinic characteristics, and their overall experience with the HPV vaccine. The session then progressed with questions that

explored providers' perceptions about parental vaccine acceptance and associated factors (barriers and concerns) and more in-depth exploration to assess providers' attitudes towards the vaccine. The investigator probed participants' responses to gain insight into the cultural and moral values that may influence their conceptualization of the vaccine and how it is subsequently framed to patients and parents.

Research Aim II

To explore attitudes, perceptions, knowledge and awareness related to the HPV vaccine among Appalachian mothers.

Similar to the interview, the focus group sessions employed a semi-structured, open-ended guide that began with general questions about participants' children (number of children, gender and ages). Participants were then asked to discuss their feelings about vaccines in general. As each session progressed, participants were asked about their: knowledge and feelings about the HPV vaccine, cervical cancer, community's perception of cervical cancer risk and the HPV vaccine, the nature (content and relationship) of communication with their daughters and healthcare providers, and sources of health information. Elicited responses were probed to assess participants' cultural values, perception of gender roles, and moral values that may influence their attitudes towards the vaccine.

Research Aim III

To measure self-reported vaccination rates and assess attitudes, perceptions, knowledge and awareness related to the HPV vaccine among a sample of young women who fall within the recommended age range (≤ 26 years) for vaccine dose completion.

The survey contained questions on demographics, region of residence, vaccination status, sexual initiation and period of vaccination, attitudes and perceptions about HPV and the vaccine, knowledge and awareness about HPV, cervical cancer knowledge and awareness, mother-daughter communication, and perceptions of maternal vaccine endorsement (Appendix I).

Perceptions of Gender Roles. Using questions culled from the adolescent version of the Attitudes toward Women Scale (AWS) developed by Spence and Helmreich,(King, Phillips, Walker, & O'Toole S, 2014) respondents' perceptions of the rights and roles of women in professional and marital relationships and in dating dynamics were assessed. These measures have been previously evaluated and have shown high internal (Cronbach's $\alpha = 0.85$) and test-retest reliability ($r = 0.81-0.86$; $p < 0.05$) (Daugherty & Dambrot, 1986; King et al., 2014) Using a 10-item scale adapted for this study, participants were asked to indicate their level of agreement with different statements (e.g., '*Women who carry condoms are easy*', '*The father should have greater authority than the mother when raising children.*') on a 5-point Likert-type scale ranging from 'strongly disagree' to 'strongly agree'.

Cervical Cancer Knowledge and Perceptions. Knowledge and awareness of cervical cancer was measured using items from the National Cancer Institute's 2013 Health Information National Trends Survey (HINTS) questionnaire. Participants' knowledge about the causes of cervical cancer and prevention strategies was tested using short multiple-choice questions. Their attitudes towards cervical cancer, specifically, and cancer in general were assessed based on their: perceptions of developing cancer, cancer beliefs (fatality, severity, preventability), and faith beliefs ('*faith will help me prevent the disease*'); each response was rated on a 5-point Likert-type agreement scale. These measures were adapted from the HINTS survey and were

previously used in a study evaluating cancer risk perceptions and beliefs in the Appalachian region (Vanderpool & Huang, 2010).

HPV Knowledge and Awareness. To measure participants' knowledge and awareness of HPV, items were adapted from the CDC's Youth Risk Behavior Surveillance (YRBS) questionnaire and the HINTS item on HPV awareness and sources of information. Participants answered a series of multiple-choice and true/false items to indicate their awareness of the vaccine, source of information, modes of transmission, expected prognosis (e.g., *HPV can cause...? HPV can go away without any treatment*), and methods of prevention.

Self-Reported Vaccination Status. Participants were asked to report their HPV vaccination status ("*Have you received the HPV vaccine?*"), and how many doses had been completed. Responses were recoded as dichotomous variables, 'vaccinated' for those who had started or completed the dose and 'not vaccinated' for those who had not initiated the vaccine series. This item was adapted from the CDC's National Immunization Survey-Teen, which is used to collect annual data on national and state level vaccination coverage. To directly measure individual susceptibility to HPV infection, the survey also asked about age of vaccine receipt and timeframe of vaccine receipt relative to sexual initiation ("*Which occurred first-your first sexual intercourse or your first HPV vaccine shot?*").

Perceptions towards HPV and the Vaccine. Using a 5-point Likert-type scale, the survey assessed participants' perceptions towards both the virus and the vaccine. These items measured susceptibility to HPV infections ("*I can get HPV*"), vaccine effectiveness ("*The vaccine cannot really prevent HPV*") and worry about side effects from the vaccine ("*I am worried about side effects from the vaccine*").

Perceived control. The survey assessed participants' perceived control over their decision to receive the HPV vaccine based on their response choices to three items (*'For me to receive the HPV vaccine is easy'*, *'The decision to receive the vaccine is beyond my control'*, *'Whether I get vaccinated is not entirely up to me'*) on a 5-point Likert-type agreement scale. Participants were also asked to indicate how much they agreed with statements developed to assess their perceptions of vaccine acceptance within their interpersonal networks. These measures were developed for the purpose of this study based on literature on the application of theories in depicting health behavior (Montaño & Kasprzyk, 2008).

Research Aim IV

To explore associations between mother-daughter sexual health communication and self-reported vaccine uptake in Appalachian Tennessee.

The survey asked true/false questions to evaluate content of mother-daughter communication on sexual health, HPV, preventive health behavior, and cervical cancer. To investigate subjective norms, the study also asked participants' to indicate their perceptions of their mother's endorsement of the HPV vaccine.

Maternal Endorsement. To assess the influence of maternal approval on vaccine acceptance among this sample of college women, we asked respondents to indicate their level of agreement, on a 5-point Likert-type scale, to three statements: *'My mother thinks I should receive the HPV vaccine'*, *'My mother thinks it would be a good idea to receive the HPV vaccine'*, *'My mother wants me to get the HPV vaccine.'* These items are similar to the measures for normative perceptions and were also developed for this study based on existing literature on the application of health behavior theoretical models (Montaño & Kasprzyk, 2008).

Mother-Daughter Communication. Study participants were asked to respond to questions assessing the content and nature of sexual health communication with their mothers. Participants first answered true or false to whether or not their mother had discussed a range of 11 sexual and reproductive health topics (e.g., safe sex practices, birth control, STI/STDs, etc.) with them. They were then subsequently asked to indicate agreement, on a 5-point Likert-type agreement scale, their reception (‘*I was receptive when my mother and I talked about*’ ...) when these topics were discussed. Lastly, to explore mother-daughter relationships, participants were asked to indicate their level of agreement with a 20-item scale designed to assess parent-adolescent communication (Barnes & Olson, 1985).

Appalachian Identity. To assess cultural identity, study participants (interview, focus group and survey) were asked to indicate whether they identified as Appalachian (‘*Do you identify as Appalachian?*’). This item was included to assess both demographic and cultural characteristics and was of particular interest considering the study’s aim to explore HPV vaccine acceptance in Appalachian Tennessee.

Data Analysis

Qualitative Analysis. Audio recordings from the interviews and focus groups were transcribed verbatim and then read in their entirety to gain familiarity with the data corpus. Each data corpus was then analyzed following an inductive thematic approach (Boyatzis, 1998; Braun & Clarke, 2006). Utilizing a hybrid of inductive and a priori methods, the principal investigator (PI) employed structural coding techniques to develop a coding scheme, labeling and categorizing participants’ responses that were relevant to the research aims. The collated codes were further analyzed by grouping similar codes and data extracts into potential thematic categories. Each category was reviewed and refined to ensure internal homogeneity within each

theme and external heterogeneity with the others (Braun & Clarke, 2006). Central and recurring themes were highlighted and then explored to identify and depict patterns of association. Finally, collated themes were compared across the interview and focus group sessions in order to identify differences and generate the most representative overlapping themes.

Quantitative Analysis. Collated survey responses were reviewed to check for completeness, outliers and distribution. Statistical analysis was limited to complete survey responses from participants between the ages of 18 to 26 years old (n=479). Descriptive statistics were calculated for both dependent and independent variables. The dependent variable was vaccine status based on self-report, measured on a dichotomous scale. Participants who reported receiving at least one dose of the vaccine were classified as vaccinated, and those who had not received any dose were classified as unvaccinated. The independent variables measured include: demographic characteristics, region of residence, attitudes and perceptions about HPV and the vaccine, knowledge and awareness about HPV, cervical cancer knowledge and awareness, mother-daughter communication, and perceptions of maternal vaccine endorsement.

Young women who reported they had been vaccinated were compared to those who had not been vaccinated. Categorical variables were compared using Chi-square tests, and continuous variables that showed normal distribution were compared using *t*-tests. For Likert-type scale items, the PI conducted tests of normality (Kolmogorov-Smirnov; Shapiro-Wilk); items with non-normal distributions were then put through a series of dimension-reduction and reliability tests, before comparing means using a Mann-Whitney test. Independent variables with significant univariate results were then plotted in a multivariate logistic regression model to explore their association with vaccine status, while also controlling for confounding.

Significance of association was determined based on a p-value of ≤ 0.05 . Quantitative data were analyzed using SPSS (IBM SPSS Statistics version 23.0).

CHAPTER 4

RESULTS

Research Aim I. To explore HPV vaccine-related attitudes and perceptions of a sample of healthcare providers in Appalachian Tennessee.

Of the 22 health care providers invited to participate in the study, 12 consented and participated in a 30-minute interview session. Participants were predominantly female (n=10), two-thirds held nursing degrees, and the others held medical degrees. About 60% identified as Appalachian, and all of the practicing providers reported that they often recommended the vaccine (Table 1).

Table 1: Demographic Characteristics of Healthcare Providers

Characteristics		N (%)
Gender	Male	2 (16.7)
	Female	10 (83.3)
County of practice	Washington ¹	8 (66.7)
	Sullivan ¹	3 (25)
	Unicoi ¹	1 (8.3)
Clinical degree	RN	3 (25)
	BSN	3 (25)
	MSN	2 (16.7)
	MD	4 (33.3)
Years in Practice	>5	1 (8.3)
	5-10	2 (16.7)
	10-15	3 (25)
	≥20	6 (50)
Practice Setting	Academic	4 (33.3)
	Clinic	3 (25)
	Health department	4 (33.3)
	Faith-community	1 (16.7)
Appalachian Identity	Yes	7 (58.3)
	No	5 (41.7)

¹County ARC-Economic status designation: ¹Transitional, ²At-risk, ³Distressed

Thematic analysis revealed themes in providers' attitudes towards the vaccine and their perceptions of the vaccine's acceptance among patients and in the community. The themes around patients' perceptions predominantly focused on parent perspectives, not the adolescent and young adult perspectives as the vaccine recipients.

Provider Attitudes. Overall, this sample of providers indicated positive attitudes towards the vaccine. Most of the providers felt that there was solid scientific evidence to endorse the vaccine: *"I've read reasonably much about it and it appears to be perfectly safe and very effective. Very effective, I mean we're starting to see the studies now...and you know they were a little bit reluctant to talk about what kind of cancer reductions they could claim because nobody had really gone that far yet, but now we're starting to see some of that data back and it's pretty impressive."* None of the providers explicitly cited resistance towards the vaccine, however upon further probe, a few providers indicated concern about the vaccine. These concerns alluded to the uncertainty of long-term side effects, the multiple dose schedule and the subsequent need for follow-up, and the vaccine's potential impact on cervical cancer screening rates: *"The only concern I think I would have is that it could potentially make people think they don't need PAPs and once you know, I think it would be easy for people to make that connection like well this is supposed to protect me against the thing that PAP smears test me for so now I don't need PAPs."*

While all of the interviewed providers indicated that they often recommend the vaccine, the way in which the recommendation was framed provided additional insight into their attitudes towards the vaccine. Most of the providers reported referring to the vaccine administration schedule or the CDC's recommendation guidelines, and only a few indicated that they emphasized its utility for cervical cancer prevention.

Barriers in practice. Some of the providers felt that there were factors within their clinical practice that may inhibit vaccine acceptance. Factors such as the associated costs of stocking and providing the vaccine and storage logistics could influence patients' accessibility to the vaccine. One provider noted, and a few others affirmed, *"the funds to keep vaccines here...there's a lot of very particular requirements for vaccines. Keeping your refrigerators at a certain temperature, it's not going to cut off those types of things."* These barriers were especially noted by providers practicing in school-based clinics, none of which currently stock the HPV vaccine. In addition, they raised the issue of the enrollment requirement for the 'Vaccine for Children (VFC)' programs, whereby clinics had to complete multiple and daunting procedures in order to be enrolled with the health department to receive coverage for uninsured and under-insured patients. Time limitations during clinic consults was also noted as a barrier to recommending the vaccine, particularly as it relates to educating patients and parents and alleviating their fears, as one provider mentioned *"It can be really rough when you've got 15 minutes budgeted for checkup, but you're going to spend 20 minutes discussing all the vaccines and you know maybe at the end of it you'll get mom to let you give one...or maybe they aren't going to give any at all."*

Providers also perceived that the lack of school-entry requirement for the vaccine was a barrier to acceptance, as providers were less likely to proactively recommend it along with other mandated vaccines such as the MMR vaccine. As one provider stated, *"the HPV of course right now kind of falls through the cracks. It's not required, it's recommended."* There was the perception that the vaccine's recommendation classification also influences parental beliefs about the vaccine's safety, as stated by another provider, *"they don't think the vaccine's safe because it's not required, so therefore it's not required because it's not safe."* Additionally,

patients were more likely to resist the vaccine since it was not required, *“If it were required we’d give it more easily, and I have a feeling if it were required some parents wouldn’t even ask what it was who might otherwise deny it.”*

Perceptions of Vaccine Acceptance. There was a mixed reaction in providers’ experience with the HPV vaccine. Some providers felt that the vaccine was becoming more acceptable compared to previous years. As described by one of the clinicians, *“I think more and more people are open to it, I think. I’ve been in the general clinic for about a year and a half, and I’ve seen the slow shift in people being open to it.”* On the flipside, a number of providers felt that there was low awareness about the vaccine. One provider reported, *“some people just haven’t...don’t know anything about it and therefore they are just hesitant to get it.”* This perception of continuous resistance was echoed by many providers who discussed experiencing parents’ hesitation when they introduced the vaccine for their daughters, *“my experience has been, that’s the one that’s most likely to be refused.”* In conceptualizing the perceived hesitation among patients, one provider succinctly categorized the vaccine as *“the colonoscopy of vaccines, it’s colonoscopies with prevented recommendation that’s most likely refused.”*

Perceived barriers for patients. The predominant theme mentioned by a number of the providers was misinformation among patients as the main barrier to vaccine acceptance: *“really the biggest barrier is just misinformation on the patient side. That’s the biggest one.”* Providers felt that the propagation of wrong information had a significant influence on patients’ attitudes towards the HPV vaccine specifically, and the ‘anti-vaccine’ movement in general. They also noted the role of the internet and social media in enabling this barrier, as one respondent stated: *“...with HPV just seems to be that there’s stuff out there on the internet that’s keeping parents from accepting it.”*

In further discussing their perception of potential barriers which may hinder patients' acceptance of the vaccine, vaccine affordability and availability, and the need for follow-up visits to complete the vaccine series were some of the predominant themes discussed by most of the providers. The issue of the vaccine's affordability as it relates to cost: *"Cost is an issue especially when it was new because you know if we were talking about getting the vaccine, a really early question would be does my insurance cover it?, "* and insurance coverage: *"so some of the barriers we have are on insurance coverage..."* were other points cited. Unavailability of the vaccine at the time of recommendation or discussion was another potential barrier discussed: *"if we don't physically have the vaccine and we have to write a prescription for it, that's one more step in the process and a lot of times patients won't take the initiative to go to the pharmacy and get that prescription and then make another appointment and come back and get the shot."* Several providers identified the multiple-dose schedule of the vaccine as a barrier to acceptance, this was discussed both in relation to their patient: *"I think it's unfortunate that the schedule of it is hard to adhere to, having people come back repeatedly I think makes it challenging to fully vaccinate people, and I think that now there's that recognition that maybe a two shot series is adequate...so that's better than three, still not as good as you know one shot all done,"* and from their perspective as patients, *"I feel like I can speak from experience, I've talked to patients 'cause I got 2 out of 3, I never went back and got the third for no good reason other than I was busy."* This barrier was further illustrated by another provider: *"I have a daughter who is a pharmacist that absolutely understands everything about HPV and she has an eleven-year-old and a thirteen-year-old and she's gotten her first shots and has never followed up on the rest."* The vaccine's delivery mechanism as a 'shot' was also discussed by multiple providers as a potential barrier for the actual vaccine recipients (adolescents and young adults)

who often relay aversion to pain “*there’s just the general fear of needles...nobody, even when I have kids that are old enough to make their own decisions, often they don’t wanna do it.*”

Specific to adolescents’ vaccine acceptance, some providers perceived that dependence on parental approval could inhibit young women from receiving the vaccine if they were willing to accept the vaccine but the parents or guardian disapproved. As discussed by one of the providers, “*Let me check with my mom first is a response that I get a lot. I don’t know if it’s their easy way of saying, ‘I’m not interested,’ or if they really and truly are checking with their mom, one to find out if insurance covers it or two that mom would approve of them getting the vaccine.*”

Parental beliefs. Respondents perceived fear of side effects as a recurring concern among parents. One provider noted that “*The parents are very worried about is it safe,*” and another provider explained, “*I have a friend who has two teenage or pre-teens and I asked, ‘Are you going to get it’? And she said, ‘No, there are too many side effects’.*” Providers stated that patients were not always able to provide medical justification for their claims of the vaccine’s side effects. The novelty of the vaccine was another perceived fear, which also related to parent’s questioning the vaccine’s safety. One provider stated that, “*a lot of parents feel like this is a new vaccine, even though the vaccine’s been around for several years, they feel like it’s still new, and therefore may not be safe.*” This perception was reaffirmed by other providers who reported they also received questions about the vaccine’s novelty and safety.

Providers also perceived that parents often considered the necessity of the vaccine for their children in relation to their age and the vaccine’s implication for sexual activity. Providers stated that parents often questioned, “*Is it necessary for my child?*” and subsequently usually decided to delay vaccine receipt, as explained by a provider, “*probably the thing would be that I*

get a lot is we're not gonna get that today, and then when she's old enough she can make her own decisions." According to providers, the question of necessity was often discussed in relation to the child's sexual activity, *"the specific resistance to the idea that my child is going to be sexually active or can be exposed to this, parents really don't want to think about that when they've got an 11-year-old."* Sexual activity was considered again in terms of parent's belief of an implied permission for sexual initiation or promiscuity once the vaccine is received, as mentioned by one provider, *"They think it's an 'okay to have sex' if they get it for their children."*

Parent's distrust of the government and pharmaceutical companies was also cited as a reason for vaccine resistance. A couple of providers noted that some parents believe, *"that it's just the pharmaceutical companies just trying to make money like there is a distrust",* and *"think that the government puts dangerous stuff in it."* In reaffirming this perception of distrust among patients, other providers also felt that it was indicative of the emerging resistance towards vaccines in general, *"the anti-vaccine movement,"* as it was described by one provider. The resulting resistance that this movement perpetuates was further explained by another provider who stated, *"I think really the biggest thing is people are suspicious of vaccines in general."*

Lastly, providers believed that the low perceived susceptibility among patients, both parents and their children, hindered acceptance of the vaccine. One provider explained that this perception was common among her patients, particularly in relation to sexual health, *"So, a lack of perceived risk which is kind of a common theme in my patient population in particular when it comes to sexual health."* This perception was re-affirmed by another provider who illustrated the point by putting it into perspective with polio, another vaccine-preventable disease, *"If people tell you, you need a vaccination for polio... uh in my age group or so people would get a polio*

vaccine right away, but we saw all the risks of it so it wasn't you know... I mean people did it because they didn't want polio and you did it for your children, because you were very worried about polio. So, to me it's a matter of whether you perceive it as something that is... um... as harmful." Other providers attributed the low perceived risk to be reinforced by low levels of awareness and education about HPV and the vaccine, *"most of the time if they say no it's because they haven't heard of it, they didn't know about it, occasionally you'll get people who say, 'no I don't want that,' but usually they just kind of look at you a little confused like I don't know what you're talking about."*

Community Perception. In discussing their perceptions of vaccine acceptance among residents of Appalachian Tennessee compared to other communities, a few providers felt that there were similar levels of acceptance. However, most of the providers felt that there was a difference in perception, with Appalachian Tennessee exhibiting more resistance compared to other regions. Some providers perceived that the difference was due to religious conservatism in the region, as illustrated by one provider, *"So I think that we're in the Bible Belt, and according to the Bible, we should wait or according to religious... ideology, we should wait until we're married to have sex, and so the thought process is, 'well my kid is not going to have sex before they are married, so why would they need that vaccine anyway?'"* Other providers felt that the difference was also influenced by the community's perception of sexual health topics in general. As explained by a provider, *"I think here there's probably a higher concentration of people who are really focused on kind of abstinence-only education for their kids...you see a lot of parents who just are not comfortable with the idea of talking about birth control or STDs or the HPV vaccine or anything having to do with sex because they just... really wanna drive home to their*

kids that abstinence is the only um you know the only choice. So I think we probably see that a little more here than in other parts of the country.”

Facilitating Vaccine Acceptance. In addition to sharing their perceptions and experiences, participants discussed effective strategies they had employed in recommending the vaccine. A recurrent theme among providers was the idea of reminding parents, in response to hesitation based on implied sexual activity from the vaccine, of their daughter’s susceptibility to STIs/STDs, as one provider stated, *“I tell parents that y’know, your daughter can be lawfully wed to one man and have sex with that person only, and still, if he brings the virus into the marriage, she’s the one that pays the price.”* Many of the providers also highlighted the health department as a resource for receiving the vaccine and other health services and indicated often referring uninsured or underinsured patients.

Participants were also asked to provide recommendations for how vaccine acceptance can be improved. Many of the providers emphasized the need to increase education and awareness about the vaccine and the diseases it prevents. One provider felt that a *“national... education campaign about HPV would probably...work.”* Other providers reaffirmed this strategy but particularly highlighted the need to directly educate adolescents, as noted by one provider, *“educating the kids themselves...education, sex education and things like that, in the schools, and including that in that conversation, talking about the HPV vaccine...as well as like other things that they need.”* Interestingly, while some providers felt that the church was also a potential setting to educate youth, one provider noted, *“I think church would be a really good setting because uh if you had a parish nurse for example, you know they’d have a captive audience as far as the parents and the teenagers.”* There was contradictory evidence from faith-community practitioners, who felt that most of the congregation sought health information from

their healthcare providers, *“from my perception, I don’t think they would tend to come to the congregation or the congregational nurse looking for information.”*

Participants also recognized and discussed their role as providers in facilitating vaccine acceptance. According to a respondent, *“one of the things that makes a difference in people getting a vaccine is providers giving a strong recommendation. So rather than saying, ‘hey do you maybe want to get a shot today?’, saying like, ‘hey I noticed that you are due for this shot, and we recommend that all of our patients get it because of X, Y, Z,’ and patients are more likely to get it if you give them kind of a confident recommendation as their provider.”* Some providers also felt that making the recommendations more personal or including scenarios that patients could relate to would increase acceptance. Additionally, some providers emphasized the need to highlight the vaccine’s effectiveness in cancer prevention instead of discussing the sex-related risk. One of the respondents perceived that framing it this way would have yielded a different reception, *“I think if they would have marketed it from day one as a cancer vaccine instead of even using the word sex, that they would have a different...”*

Research Aim II. To assess attitudes, perceptions, knowledge and awareness related to the HPV vaccine among Appalachian mothers.

During the 3-week period between November and December 2016, three focus groups were conducted. A total of 13 mothers (mean age= 47.5 years) attended and participated in a discussion, and shared their opinions and experiences on the HPV vaccine, cervical cancer and health communication. About two-thirds (n=8) of the participants identified as Appalachian, over 50% of the participants had at least a college degree, all participants indicated some type of health insurance coverage, and all were employed (Table 2). About two-thirds (n=8) of mothers

reported vaccinating their daughters against HPV, six of whom also reported receiving a provider's recommendation for the vaccine (Table 3).

Table 2: Demographic Characteristics of Focus Group Participants

<i>(N = 13)</i>		
Characteristics		N (%)
County		
	Carter ²	1 (7.7%)
	Greene ²	1 (7.7%)
	Hancock ³	5 (38.5%)
	Washington ¹	5 (38.5%)
Appalachian Identity		
	Yes	8 (61.5%)
	No	5 (38.5%)
Marital Status		
	Married	9 (69.2%)
	Divorced	4 (30.8%)
Education		
	High school diploma/GED	1 (7.7%)
	Associate degree	2 (15.4%)
	College degree	3 (23.1%)
	Graduate degree	7 (53.8%)
Employment		
	Full-time	11 (84.6%)
	Part-time	2 (15.4%)
Household income		
	\$35,000-\$50,000	4 (30.8%)
	\$50,000-\$75,000	4 (30.8%)
	≥\$75,000	5 (38.5%)
Health Insurance		
	Employer sponsored	9 (69.2%)
	Private	2 (15.4%)
	Military healthcare	1 (7.7%)
	State-Sponsored	1 (7.7%)

County ARC-Economic status designation: ¹Transitional, ²At-risk, ³Distressed

Table 3: Provider Recommendation and Daughter's Vaccination Status

		Vaccination Status		X ² {p-value}
		N (%)		
		Yes	No	
Provider Recommendation	Yes	6 (46.2)	3 (23.1)	5.45 (p=0.065)
	No	2 (15.4)	2 (15.4)	

Attitudes towards HPV vaccine. Most of the focus group participants had heard of the vaccine, although their level of awareness varied. The mothers who had heard about the vaccine reported hearing about it from their healthcare providers or through television advertisements. Their attitudes towards the vaccine were predominantly positive, and most of the participants emphasized the protective attributes of the vaccine. Upon being asked to describe the vaccine in one word, participants' responses included: "protection," "safety," "cancer," "needed", "prevention," and "benefit." 'Protection' was the primary theme, and it was directed at the vaccine's utility in cancer prevention. One mother said, "This is a vaccine that could possibly prevent my child from having cancer in the future. Why would I not come in here and get this vaccine?" Many of the mothers felt that receiving the vaccine was standard practice and drew parallels between the HPV vaccine and other administered vaccines, as illustrated by one mother, "Well you think and we give them [MMR], we give them chicken pox, and chicken pox is not a horrible thing to go through. I lived through it, but I give them a vaccine for that so why not give them a vaccine for something that could very well save their life?" This notion was affirmed by other participants, one of whom also noted the vaccine's utility in protecting her daughter against reproductive health issues resulting from cervical cancer.

Perceptions towards resistance. While many of the participants conveyed positive attitudes towards the vaccine, both mothers who had their daughters vaccinated and those who

had not, relayed concerns about the vaccine. The primary factors of concern were: worry about side effects, the newness of the vaccine, perceived lack of effectiveness, and necessity of the vaccine at the recommended age (11 to 12 years old). Due to perceived side effects, one mother relayed regret in vaccinating her daughters, *“looking back now ... I don’t know if I would necessarily elect to still have the HPV [vaccine], I don’t know if this has anything to do with it...but both of my daughters are chronically ill with blood pressure issues... I don’t know if it has anything to do with that, I just know that they are saying they would like to do some studies to see if there’s been any kind of a link to that... I see them now and it makes me worry that my decision to make sure that they were safe was the decision that may not have been...”* One participant reported hearing about reports of potential side effects from the scientific community. She said, *“after my daughter got it [vaccine], all that information came out about the doctor who developed it, and I think was she from UVA maybe, and there was all these things about how she was saying she regretted ever developing it and issues it could cause later.”* Another mom also affirmed the fear of side effects especially as it relates to the amount of time the vaccine has been on the market. This mother reports that she, *“held off because... just mixed feelings. Brand new vaccine, don’t know what side effects were.”* The concern about the vaccine’s novelty was a recurring theme, which participants related to its safety and effectiveness. As one mother stated, *“It is newer... that would be one thing that I would worry about.”* In both focus groups, participants also questioned the vaccine’s long-term effectiveness and worried about sustained immune response over several decades. As stated by one participant, *“I don’t know if it’s been around long enough to have these longitudinal studies where you see how long does it last... in other words, does it at some point lose its strength,”* and another participant who worried about

the vaccine's effectiveness in cancer prevention, "*What if it don't work?...what if it makes it worse?*"

For some mothers, the recommended age range for vaccine initiation created hesitation, as they did not feel that the vaccine was necessary for their younger children, and thus delayed vaccine receipt. One participant felt that, "*at this point in time that I want them to have it before they become sexually active... but when I'm dealing with an 11- and 13-year-old... I've got a couple years, and I'm kind of wanting them to have a little more physical maturity.*" In both focus groups, participants discussed perceptions, among their family and social networks, about the vaccine's implication for sexual activity: "*I did hear from a distant family member, that they felt like getting that vaccine somehow gave your children permission to be promiscuous.*"

However, many of the participants debunked the notion. As one participant illustrated, "*that argument about, that some people do make still, about how you know they are worried that HPV vaccination in particular will lead to promiscuity which I find bizarre like you [participant] do, but it's like what? I mean does getting the MMR vaccination make you go out and actively seek measles? I don't think so.*"

Some participants also noted additional areas of concern about the HPV vaccine, specifically, and vaccines in general. One group of mothers stated concern that vaccination could lead to a sense of false safety and potential delinquency on screening practices. As one participant stated, "*I made sure that my oldest daughter understood that you know once you became sexually active how important it was to still have your annual exams that just because you had HPV shot doesn't mean I don't ever have to be checked for anything because that is so far from the truth.*" Some participants also discussed aversion to vaccines in general. One mother said, "*Shots make me nervous.*" Due to her daughter's previous adverse reactions from the flu

shot, one mother who had not vaccinated her daughter stated, *“I hesitate injecting another virus or series of viruses into my child that their body may or may not develop an immunity to.”*

Motivations for vaccine acceptance. For mothers who had vaccinated their daughters, the primary reason for accepting the vaccine was to prevent cancer. Some mothers illustrated this motivation based on their fear of cancer, *“I think I just hear the word cancer and the first thing in my mind goes whatever we can do to make that not happen for my kid... I’m ready to go.”* Some discussed vaccine acceptance in terms of long-term protection for their daughters and future generations. One mother felt *“...not only is this protecting my daughter, it’s protecting anyone she comes in contact with...it’s protecting future generations...it’s maybe something that my grandkids wouldn’t have to worry about if we can continue to get people vaccinated”*. One mother discussed family approval as her reason for vaccinating her daughter in her statement, *“my parents... would have been 100 years old right now... they believed in vaccinations. They remembered things like when polio was [rampant]...it was like take advantage of these things that could help prevent disease and conditions whatever you need to do as long as it’s safe.”*

Participants also emphasized the theme of cancer prevention, particularly based on personal or family history of cancer. One mother, who is a cervical cancer survivor, emphasized her point in reliving her experience and regretted that the vaccine was unavailable for her as a child, *“I wish I had had the shot so then I wouldn’t have to, you know I did have cervical cancer. So, that’s why I had to have the hysterectomy, and we had one kid, and then we were done. So, if the shot had been available, I hope that my mom would have said you’re getting it. If it would have prevented any of that... ’cause I don’t want her to get cancer. I don’t want her to have to go through the same thing that I went through.”* Another participant accepted the provider’s recommendation to vaccinate her daughters because, *“both of my grandmothers had cervical*

cancer, and I thought, 'well, if this is a way to prevent that then that would be a great thing to do,' like she [provider] said something... 'you could protect your children from um...' So, we elected to do both of them."

Additionally, the theme of protection was also discussed in relation to perceived sexual vulnerability of their daughters. Some participants were motivated to accept the vaccine for their daughters in the incident of an involuntary sexual encounter. One mother mentioned that, *"they may intend not to be sexually active before they are married, but that's not to say that they're not grabbed by somebody on the street either."* This notion was reaffirmed by another mother who said a convincing factor for her was the provider's inference of potential exposure to the HPV virus even in marriage. According to her, *"when the doctor heard that question [necessity of the vaccine without sexual initiation] his answer was, 'but you don't know about the person you might marry and what they might have done prior to meeting you'...I think that was one of the two turning points for me."*

In discussing their decisions on whether or not to accept the vaccine, weighing the perceived risks versus the expected benefits was a recurrent theme among many of the focus group participants. One mother stated, *"you do the risk benefit ratio thing and I could only see the benefit."* Another mother considered the perceived risk to the benefit of cancer prevention and reported, *"I read through the information, and I know that every vaccine has side effects, but...if the advantages are going to outweigh the side effects, I thought cancer and side effects.... I'll go for vaccine."* One mother that felt quite strongly about preventing cancer stated, *"if three shots can prevent it, three... even if I had to hold her down for them to give those shots. And in all honesty if they had said cut her big toe off on one of her feet if that would mean she would never get cancer, I would probably do it."*

Participants who had vaccinated their daughters reported doing so after receiving a recommendation from their healthcare providers. One mother mentioned hearing about the vaccine from her physician who *“highly recommended it and planned for his own children to have it, and he said he strongly recommended it be done.”* Other mothers reiterated this factor, buttressing the point that established trust or relationship with the provider made the recommendation stronger, one mother said, *“the other factor was the doctor...has kind of developed a relationship with my kids, and they trust her so much...If the doctor said it, it is okay.”* Another mother mentioned that these combined factors were of particular importance in her community, *“because we are so small, I think they almost value a [provider’s] personal opinion as much as they do anything else.”* Additionally, one mother stated that notification of coverage from her insurance company motivated her to accept the vaccine for her daughter.

Finally, participants reported that the vaccine’s inclusion on the regular vaccine schedule or specifically for their child’s age range was enough reason for them to vaccinate their daughters. One mother stated that she, *“would be okay saying that the government says I have to give you this, so suck it up,”* and another mother said she accepted the vaccine because, *“She’s eligible to have it at this age...Let’s do it.”* However, despite their stated motivations to accept the vaccine, some of the participants reported they rarely approved vaccine receipt immediately upon recommendation and often delayed their decision. This delayed reaction was reportedly because of the age range that the vaccine could be received. According to one mother who eventually received the vaccine for her daughter, *“To me that was one thing about the HPV was that you had this range time that it could be given which I felt like kind of bought you some time.”*

Perceived Control. When asked whether they felt it was in their control to accept the vaccine for their daughters, many of the mothers felt that the decision to vaccinate was within their control. The participants emphasized the role of women and mothers in making general healthcare decisions for their family, as stated by one of the participants, *“it’s usually women...for themselves and for everybody...”* In considering the HPV vaccine specifically, participants also felt primarily in control as wives, as illustrated, *“[my husband] almost would let me chop the kids’ arms off if I thought that’s what needed to be done,”* and as mothers, *“I wouldn’t leave it up to [daughter], she doesn’t want to have a shot...so, that would be completely in my control.”* In addition, some of the participants felt that the vaccine’s status as ‘recommended,’ not ‘required,’ gave them control on whether or not to vaccinate their daughter, as reflected in this mother’s statement, *“The school... requires me to have certain ones, but the HPV is not one of those, so this particular vaccine is all in my control.”*

Perception of daughter’s attitudes. In reflecting on their daughter’s attitudes towards the vaccine, many participants agreed that their daughters exhibited fear or dislike of shots. One mother said, *“My daughter had such a fear of needles at the time, I kind of gave her a little bit [of] time.”* Another participant reported discussing the vaccine with her daughter who was fearful of getting the vaccine, *“my daughter had started hearing things about it [vaccine] from her friends who had had it that talked about how much the shot hurt and how some of them had actually passed out from it, and so that was more of a frightening thing for her.”* Participants also discussed their daughters’ questioning the necessity of the vaccine in the absence of sexual activity. A participant reported that her daughter asked, *“if you’re not having sex, do you need to get this shot?”* One mother mentioned that her daughter made a self-informed decision to receive the vaccine and considered it standard routine, *“when the doctor told us about the vaccine...we*

went home with this long handout, and she read so it wasn't even coming from us as parents, she read that and just like well, yeah just like the other vaccines."

Health communication. In discussing mother-daughter health communication, some participants reported talking to their daughters about health topics such as hygiene, nutrition, and personal health conditions. Most participants reported difficulty in talking about sex-related topics with their daughters. One mother reported that she, *"had a hard time with it,"* and another mother felt it was also difficult for the daughters to engage in such conversations with them, *"She don't want to talk about stuff like that with me, it is a little awkward."* Participants stated a desire to engage in conversations around sex and reproductive health with their daughters in order not to repeat history; as discussed by one mother who reported having these conversations with her daughters in the past, *"we just read some things...and somehow that allowed us to talk about some issues that our parents did not discuss with us... and it was new for us because we come from a culture where some of the sexual talk is taboo. Nobody, mom didn't mention anything like that to me, so we are trying it as parents"* Some mothers also indicated a desire for sex education to be delivered in the schools, *"I would be okay if we had... somebody in the school system, somebody from the health department that would come and talk to them."* In discussing the HPV vaccine specifically, one of the participants reported that she, *"would feel comfortable talking to my kids about it...About the shot... probably not as much about the reason....Just you know this could stop you from having cancer or I wouldn't want to say this will stop you from having cancer when you start to have sex."*

When asked about their sources of health information, most of the focus group participants cited their healthcare provider and the internet as their primary source. Some mothers reported searching sites such as WebMD, and others got their information from social

media, Facebook specifically. Many of the participants reported their healthcare providers had talked to them, and in some cases also their daughters, about the vaccine. One mother said, *“I didn’t go in and ask for it. I was just getting my school shots, they brought it up to me.”*

However, most of the participants reported that they did not often discuss HPV, the vaccine or cervical cancer within their social circles. They stated that this was not due to a lack of willingness to engage in these conversations but, as one mother stated, because, *“it doesn’t come up... I mean if it came up organically you know I would talk.”* Another participant also felt that discussions around cervical cancer and its preventive measure were not often initiated because, *“It’s not one of the sexy cancers.”*

Perceptions of community’s acceptance. There was variability in participants’ perceptions of approval of the vaccine within their social networks. While some felt that people who were close to them would approve of the vaccine, either because they believed in the necessity of vaccines in general or in the utility of the HPV vaccine in cancer prevention, others felt that there would be some level of disapproval. These participants felt that the disapproval would be mostly from older generations who often equated vaccine acceptance with permission for sexual activity, as one mother cited, *“I think in a certain circle they would be supportive...but older people may not feel that same way. I’ve heard older people say well I don’t know why these parents are giving them this shot because all that does is like give them permission to go ahead and get sexually active.”*

In discussing their perceptions of vaccine acceptance among residents of Appalachian Tennessee compared to other communities, participants felt that people in their communities were more likely to exhibit negative attitudes towards the vaccine primarily based on the implied sex-related attribute of the vaccine. Participants reported being dissuaded against the vaccine by

both family members and health professionals. One mother said she “*did hear from a distant family member, that they felt like getting that vaccine somehow gave your children permission to be promiscuous,*” and another cited her experience at point of vaccine receipt, “*I took her in uh to the doctor’s office... and one of the other nursing people said um why are you getting the sex vaccine?*” These statements were reaffirmed by other mothers in the focus groups who had experienced similar situations. Participants felt that this attitude towards the vaccine was largely due to the religious conservatism in the area; as one mother illustrated, “*I think religion plays a little bit of a part too. It’s all about your morals. You do not have premarital sex. You know a 16-year-old shouldn’t even be doing that. Why would you even consider [vaccine]?*” and the sexual communication climate in the state, both in personal lives and within the school system, as explained by one of the participants, “*...in Tennessee they don’t let you talk about things like that in school systems,* and echoed by another, “*It is I don’t talk about it or think about it, it doesn’t exist...that’s a negative coping skill we see a lot here.*”

Perceived barriers in region. While participants did not indicate personal barriers to receiving the vaccines for their daughters, they felt that barriers existed within the community that inhibited vaccine acceptance. Some participants felt that affordability of the vaccine could present significant challenges, because according to one mother, “*the biggest barrier is poverty... The HPV vaccine is very expensive... I think it was over \$200 for one, but you consider the whole series.*” Participants also cited accessibility to health facilities and the resultant low utilization of preventive services as a major barrier, as explained by one participant, “*The emergency room is still the primary care physician for a lot of people that I know,*” and echoed by another, “*a lot of people don’t go...for routine stuff.*” Additionally, some participants felt that low education and awareness about the utility of the vaccine and available health services were

significant barriers to vaccine acceptance. In one of the focus groups, a participant stated, “*our whole community needs education.*” Across both focus groups, the phrase ‘*knowledge is key (power),*’ was repeated by different participants, as one of them illustrated, “*knowledge is key, because if... if there’s a [free] vaccine somewhere you have to know that you need it...someone has to tell you that that shot means something for your life.*” Lastly, some participants considered parental consent to receive the vaccine as a significant barrier. One mother stated, “*I wish that they could get it...that they didn’t have to have parental permission to come in and get the shot.*”

Research Aim III. To measure vaccination rates and assess attitudes, perceptions, knowledge and awareness related to the HPV vaccine among a sample of young women who fall within the recommended age range (<26 years) for vaccine dose completion.

About 60% of participants (n = 287) reported they had received at least one dose of the vaccine, about half (n=160, 56.7%) of whom had completed the 3-dose vaccine series, and 40% (n=192) reported never initiating vaccine receipt. Of those who had been vaccinated, about one-third (n = 85) reported receiving their first vaccine dose after their first sexual intercourse. Table 4 shows the demographic distribution of respondents. Most participants were between the ages of 18 and 22 years old, 40% identified as Appalachian, and region of residence was almost equally distributed between rural and sub-urban.

Of the respondents who identified as Appalachian, about 45% (n =217) reported residing in counties within Appalachian Tennessee (Table 5). Other respondents primarily reside in counties in either non-Appalachian regions of Tennessee, or other parts of the country.

Table 4: Demographic Characteristics of Survey Respondents

(N=479)		
Characteristics		N (%)
Age	18-22	457 (95.4)
	23-26	22 (4.6)
Region of Residence	Rural	209 (43.8)
	Sub-urban	202 (42.3)
	Urban	66 (13.8)
Appalachian Identity	Yes	191 (40%)
	No	287 (60%)

Table 5: Respondents' Distribution by Appalachian Identity and County of Residence

		County of residence N (%)		X ² {p-value}
		Appalachian TN	Other	
Appalachian Identity	Yes	96 (20.0)	95 (19.8)	69.96 (p <0.001)
	No	121 (25.3)	166 (34.7)	

Further analyses investigated associations between hypothesized predictor variables and vaccination status. The distribution of vaccination status by Appalachian identity and region of residence did not show statistical significance. Most participants who had been vaccinated indicated that they had received the vaccine recommendation from their provider and also reported previous awareness of the HPV virus (Table 6).

On average, participants who had received the vaccine had higher mean scores (M= 8.67; S.D. = 1.82) on knowledge about HPV's risks, related diseases, symptoms, modes of transmissions and preventive measures, compared to those who had not been vaccinated (M= 8.42; S.D=1.78). However, these differences (0.24; 95% C.I. = -14-0.62) were not statistically significant (t (377) = 1.24, p=0.46).

Table 6: Descriptive Analysis of Hypothesized Variables and Vaccination Status

		Vaccination Status		
		N (%)		
Variables		Yes	No	X ² {p-value}
Region of residence	Rural	130 (27.3)	79 (16.6)	1.325 (p=0.516)
	Urban	119 (24.9)	83 (17.4)	
	Sub-urban	36 (7.5)	30 (6.3)	
Appalachian Identity	Yes	119 (24.9)	72 (15.3)	0.678(p=0.410)
	No	168 (35.2)	119 (24.9)	
HPV Awareness	Yes	244 (51.0)	134 (28.0)	16.732(p<0.001)
	No	42 (8.8)	58 (12.1)	
Provider recommendation	Yes	193 (55.5)	63 (18.1)	48.836 (p<0.001)
	No	32 (9.2)	60 (17.2)	

Overall, the distribution of median scores for participants' perceptions of equality in gender roles ($U=31.578$; $z=2.72$; $p<0.05$) and normative beliefs ($U = 11,528$; $z = -10.78$; $p = <0.001$) differed by vaccination status (Table 7). Participants who had been vaccinated also had higher positive perceptions of gender roles ($Mdn = 1.57$; $IQR = 0.86$) and higher agreement ($Mdn = 4.00$; $IQR = 2.00$) that the vaccine was acceptable within their interpersonal network compared to those who had not initiated vaccination ($Mdn=1.86$; $IQR = 1.29$; $Mdn = 3.00$; $IQR = 0.67$, respectively). Additionally, perception of maternal endorsement of the vaccine differed significantly among those who had been vaccinated compared to those who had not been vaccinated ($U = 9, 610$; $z = -11.94$; $p = <0.001$). Students who had not initiated vaccine uptake had higher disagreement ($Mdn = 3$; $IQR = 1.00$) that their mother approved of the vaccine compared to those who report vaccine uptake ($Mdn = 4$; $IQR = 2$).

Table 7: Mann-Whitney U Test Comparing Participants' Perceived Norms

Variables	Vaccination Status		Test Statistics
	Yes Median(IQR)	No Median (IQR)	
Perception of equality gender roles	1.57(0.86)	1.86(1.29)	U=3,578; z=2.72; p<0.05
Perceived norms	4.00(2.00)	3.00(0.67)	U=11,528; z= -10.78; p<0.001
Perception of maternal endorsement	4.00(2.00)	3.00(1.00)	U=9,601; z= -11.94; p<0.001

Comparing participants' perceptions towards both the vaccine and the virus, there was a weak statistical difference ($p=0.05$) in perceived susceptibility to HPV infection by vaccination status (Table 8). However, participants who had received the vaccine had higher agreement that the vaccine would be effective in preventing HPV, and indicated less concern about potential side effects from the vaccine. Also, while the agreement rates for perceived control in decision to receive the vaccine did not show statistical difference across each category, students who had received the vaccine had higher perceived ease of vaccine receipt (Mdn=2.00; IQR =1.00) compared to those who had not received the vaccine (Mdn=3.00; IQR=1.00).

Final logistic regression models analyzed relationships between significant predictor variables and vaccination status (Table 9). The results of the analyses indicated that the model was a good fit with an overall predictive accuracy of 83%. Univariate analysis of the predictor variables showed that positive perceptions of gender roles, perceived norms, maternal endorsement, provider recommendation, and perceived vaccine effectiveness, potential side effects, and ease of getting the vaccine were all associated with vaccine acceptance, while Appalachian identity did not show significant association.

Table 8: Mann-Whitney U Test Comparing Participants' Perception Towards HPV and The Vaccine

Variables	Vaccination Status		Test Statistics
	Yes Median(IQR)	No Median (IQR)	
I can get HPV	3.00(1.00)	3.00(1.00)	U=29,298; z=1.95; p=0.05
The vaccine cannot really prevent HPV	2.00(1.00)	3.00(1.00)	U=32,817; z=4.64; p<0.001
I am worried about side effects from the vaccine	2.00(2.00)	3.00(2.00)	U=37,041; z=7.68; p<0.001
For me to receive the HPV vaccine is easy	3.00(1.00)	2.00(1.00)	U=36,660; z=7.42; p<0.001
The decision to receive the vaccine is beyond my control	2.00(2.00)	2.00(2.00)	U=25,624; z= -0.60; p=0.546
Whether I get vaccinated or not is not up to me	3.00(2.00)	3.00(2.00)	U= 25,911; z= -0.32; p=0.75

After controlling for confounding, multivariate analysis showed that maternal endorsement, provider recommendation, and concern about potential side effects from the vaccine were strongly associated with vaccine acceptance. Perception of normative approval also showed moderate association ($p=0.05$) with vaccine acceptance.

Provider recommendation was the greatest predictor of vaccine acceptance. Compared to those who had not been vaccinated, participants who had been vaccinated were more than four times ($OR=4.59$; $CI=2.36-8.93$; $p<0.001$) as likely to have received a provider's recommendation for the vaccine. Participants who had received the vaccine were almost twice as likely ($OR=1.95$; $CI= 1.32-2.88$; $p=0.001$) to agree that their mother approved of vaccine receipt compared with those who had not been vaccinated. Participants who had been vaccinated were also less likely to indicate concern about potential side effects from the vaccine. Finally, those who had been

vaccinated were 57% (OR= 1.57; CI= 1.00-2.47; p= 0.05) more likely to perceive that people within their social circles would approve of their vaccine receipt compared to those who had not been vaccinated.

Table 9: Univariate and Multiple logistic regression analyses showing association between hypothesized predictor variables and vaccination status

Predictor Variable	Crude OR	95% C.I	P-value	Adjusted OR	95% C.I	P-value
Perceptions of gender roles	0.68	0.53-0.87	<0.05	1.00	0.63-1.58	0.99
Perceived norms	3.33	2.63-4.22	<0.001	1.57	1.00-2.47	0.05
Maternal endorsement	3.41	2.60-4.46	<0.001	1.95	1.32-2.88	0.001
Provider recommendation						
Yes	5.74	3.43-9.61	<0.001	4.59	2.36-8.93	<0.001
No	-	-	-	-	-	-
The vaccine cannot really prevent HPV			<0.001			0.87
Strongly disagree	2.70	0.78-9.34	0.12	0.52	0.06-4.62	0.56
Moderately disagree	2.01	0.64-6.25	0.23	0.96	0.13-6.98	0.97
Neutral	0.76	0.25-2.34	0.63	0.97	0.13-7.16	0.98
Moderately agree	0.99	0.28-3.42	0.98	0.80	0.10-6.22	0.83
Strongly agree	-	-	-	-	-	-
I am worried about side effects from the vaccine			<0.001			<0.05
Strongly disagree	11.64	4.83-28.83	<0.001	2.34	0.60-9.07	0.22
Moderately disagree	5.46	2.25-13.26	<0.001	2.76	0.73-10.36	0.13
Neutral	2.75	1.19-6.36	<0.05	2.46	0.68-8.84	0.17
Moderately agree	1.46	0.58-3.65	0.42	0.69	0.18-2.63	0.58
Strongly agree	-	-	-	-	-	-
For me to get the vaccine is easy			<0.001			0.14
Strongly disagree	6.33	1.87-21.44	<0.01	1.40	0.17-11.04	0.75
Moderately disagree	2.22	0.68-7.28	0.19	0.55	0.07-4.28	0.57
Neutral	0.69	0.21-2.32	0.55	0.47	0.06-3.90	0.48
Moderately agree	1.72	0.44-6.72	0.43	1.12	0.12-10.74	0.92
Strongly agree	-	-	-	-	-	-

Stratified regression analyses of the significant variables by Appalachian identity revealed some differences (Table 10). Predictive associations among respondents who did not

identify as Appalachian showed similar patterns with the larger sample; perception of maternal endorsement, receiving a provider's recommendation, perception that the vaccine is acceptable within their social circles, and concern about vaccine side effects were significantly associated with vaccine acceptance. However, among respondents who identified as Appalachian, perception that their mothers' approved of the vaccine and receiving a provider's recommendation were almost equally associated with vaccine acceptance.

Table 10: Univariate and Multiple logistic regression analyses showing association between hypothesized predictor variables and vaccination status grouped by Appalachian Identity

Predictor Variable	Appalachian Identity (No) N=197			Appalachian Identity (Yes) N=144		
	Adjusted OR	95% C.I	P-value	Adjusted OR	95% C.I.	P-value
Perceived norms	1.84	1.03-3.26	0.04	1.26	0.61-2.62	0.53
Maternal endorsement	1.79	1.09-2.94	0.02	2.47	1.28-4.76	<0.01
Provider recommendation						
Yes	4.77	2.07-10.98	<0.001	4.10	1.45-11.60	<0.01
No	-	-	-	-	-	-
I am worried about side effects from the vaccine			0.05			0.29
Strongly disagree	3.28	0.53-20.11	0.20	1.78	0.26-12.00	0.55
Moderately disagree	1.59	0.27-9.19	0.61	4.84	0.66-35.76	0.12
Neutral	1.16	0.21-6.32	0.87	3.93	0.67-23.11	0.13
Moderately agree	0.42	0.07-2.59	0.35	1.42	0.20-10.28	0.73
Strongly agree	-	-	-	-	-	-

Among respondents who identified as Appalachian, perception of maternal endorsement of the vaccine showed stronger predictive association (OR = 2.47, P <0.01) with vaccine acceptance compared to respondents who did not identify as Appalachian (OR = 1.79, P<0.05).

Research Aim IV. To explore associations between mother-daughter sexual health communication and vaccine uptake in Appalachian Tennessee.

The survey assessed maternal communication in three categories: content of mother-daughter communication, participants' reception and satisfaction with mother-daughter communication, and overall mother-daughter relationship.

Most participants reported discussing at least one of the eleven topics with their mothers. There was a statistically significant difference in the distribution of mother-daughter sexual health communication by vaccination status. Participants who had been vaccinated reported talking to their mother about birth control, safe sex practices, sexual intercourse, HPV vaccination, and cervical cancer screening, more often than those who had not been vaccinated (Table 11).

Table 11: Mother-Daughter Communication and Vaccination Status

		Vaccination Status		
		N (%)		
<i>“My mother talked to me about...”</i>		Yes	No	X ² {p-value}
Birth control	Yes	229 (48.9)	134 (28.6)	5.40 (p<0.05)
	No	53 (11.3)	52 (11.1)	
Safe sex practices	Yes	210 (44.9)	114 (24.4)	9.14(p<0.05)
	No	72 (15.4)	72 (15.4)	
Sexual intercourse	Yes	213 (45.6)	123 (26.3)	5.19(P<0.05)
	No	68 (14.6)	63 (13.5)	
HPV vaccination	Yes	205 (44.0)	75 (16.1)	48.87 (p<0.001)
	No	76 (16.3)	110 (23.6)	
Cervical cancer screening	Yes	178(38.3)	85 (18.3)	14.89 (p<0.001)
	No	102 (21.9)	100 (21.5)	

Reception of mother-daughter sexual health communication differed significantly among those who had been vaccinated compared to those who had not been vaccinated (U =22,468; z =

-2.63; $p = <0.05$). Those who reported not receiving the vaccine were less receptive (Mdn = 3.18; IQR = 1.80) when their mothers talked to them about a range of sexual and reproductive health topics compared to those who reported vaccine receipt (Mdn = 3.55; IQR = 1.91). Participants who had been vaccinated reported higher satisfaction ($U = 23,093$; $z = -2.24$; $p = <0.05$) with the overall communication with their mothers (mean rank = 244.82; Mdn = 4.00, IQR = 2.00) compared to those who had not been vaccinated (mean rank 217; Mdn = 4.00, IQR = 2.00).

Additionally, as illustrated in Table 12 above, participants' overall relationship satisfaction with their mothers differed significantly among those who had been vaccinated compared to those who had not been vaccinated ($U = 22,184$; $z = -2.77$; $p = <0.006$).

Table 12: Mann-Whitney U Test Comparing Participants' Mother-Daughter Communication

Variables	Vaccination Status		Test Statistics
	Yes Median(IQR)	No Median(IQR)	
Reception of communication	3.55(1.91)	3.18(1.80)	$U = 22,468$; $z = -2.63$; $p = <0.05$
Satisfaction with communication	4.00(2.00)	4.00(2.00)	$U = 23,093$; $z = -2.24$; $p = <0.05$
Satisfaction with relationship	4.13(1.43)	4.00(1.67)	$U = 22,184$; $z = -2.77$; $p = <0.05$

Those who reported vaccine acceptance (Mean rank = 248.05; Mdn = 4.13; IQR = 1.43) perceived their relationships with their mothers more positively compared to those who had not been vaccinated (Mean rank = 212.77 Mdn = 4.00; IQR = 1.67). Specifically, there was no significant difference in the distribution of participants' perception of their mother's availability to talk with them, however participants differed in their perceptions that their mothers empathized with specific situations they discussed ($U = 22,521$; $z = -3.312$; $p = 0.001$). Those who reported vaccine acceptance indicated higher agreement that their mothers empathically

conversed with them (mean rank = 209.20; Mdn = 4.00; IQR = 1.33) compared to participants who had not been vaccinated (mean rank = 250.41; Mdn = 4.00; IQR = 1.67).

Triangulation of Findings

Analysis of findings from the interviews with healthcare providers and focus groups with mothers revealed several crosscutting themes (Table 13). Participants in both groups considered: affordability of the vaccine, aversion to pain (fear of needles), the lack of school-entry requirement for the vaccine, concern about vaccine safety, novelty of the vaccine, perceived implication of sexual activity, necessity of the vaccine for adolescents, and low education/awareness about HPV and the vaccine, as potential barriers to vaccine acceptance. Participants further inferred that these barriers were in part due to the influence of religious values and culture around sexual health within the community. Interestingly, the theme that receipt of the vaccine could lead to a decline in cervical cancer screening rates emerged as a concern across both groups. Convergent themes on facilitators of vaccine acceptance revealed that: emphasizing benefits for cancer prevention, receiving a strong and personal provider recommendation, intention to protect women in the event of involuntary sexual encounters, and including the vaccine on the schedule of required vaccines, were likely to increase vaccination rates.

Table 13: Convergent Themes from the Interviews and Focus Groups

Themes	Provider quotes	Mother quotes
Barriers to vaccine acceptance		
Affordability	<i>Cost is an issue especially when it was new because you know if we were talking about getting the vaccine, a really early question would be does my insurance cover it?"</i>	<i>The HPV vaccine is very expensive... I think it was over 200 for one, but you consider the whole series."</i>

Table 13 continued: Convergent Themes from the Interviews and Focus Groups

Pain averse	<i>...There's just the general fear of needles...nobody, even when I have kids that are old enough to make their own decisions, often they don't wanna do it."</i>	<i>My daughter had started hearing things about it [vaccine] from her friends who had had it that talked about how much the shot hurt and how some of them had actually passed out from it and so that was more of a frightening thing for her."</i>
Vaccine requirement	<i>...The HPV of course right now kind of falls through the cracks. It's not required, it's recommended."</i>	<i>The school... requires me to have certain ones, but the HPV is not one of those so this particular vaccine is all in my control.</i>
Concern about vaccine safety	<i>I have a friend who has two teenage or pre-teens and I asked are you going to get it? And she said no, there are too many side effects."</i>	<i>Held off because... just mixed feelings. Brand new vaccine, don't know what side effects were</i>
Novelty of the vaccine	<i>a lot of parents feel like this is a new vaccine, even though the vaccine's being around for several years, they feel like it's still new, and therefore may not be safe.</i>	<i>It is newer... that would be one thing that I would worry about</i>
Implied sexual activity	<i>They think it's um an okay to have sex um if they get it for their children."</i>	<i>Did hear from a distant family member, that they felt like getting that vaccine somehow gave your children permission to be promiscuous</i>
Age appropriateness/necessity	<i>The specific resistance to the idea that my children is going to be sexually active or can be exposed to this, uh parents really don't want to think about that when they've got an eleven-year-old</i>	<i>At this point in time that I want them to have it before they become sexually active... but when I'm dealing with an 11 and 13-year-old... I've got a couple years and I'm kind of wanting them to have a little more physical maturity.</i>
Low education/awareness	<i>The specific resistance to the idea that my children is going to be sexually active or can be exposed to this, uh parents really don't want to think about that when they've got an eleven-year-old</i>	<i>Knowledge is key because if... if there's a [free] vaccine somewhere you have to know that you need it...someone has to tell you that that shot means something for your life</i>
Community context		
Religious conservatism	<i>So I think that we're in the Bible belt and according to the Bible we should wait or according to religious... ideology we should wait until we're married to have sex and so the thought process is well my kid is not going to have sex before they are married so</i>	<i>I think religion plays a little bit of a part too. It's all about your morals. You do not have premarital sex. You know a 16-year-old shouldn't even be doing that. Why would you even consider [vaccine]?</i>

Table 13 continued: Convergent Themes from the Interviews and Focus Groups

	<i>why would they need that vaccine anyway?</i>	
Abstinence-only sex education	<i>I think here there's probably a higher concentration of people who are really focused on kind of abstinence only education for their kids</i>	<i>In Tennessee they don't let you talk about things like that in school systems</i>
Concern about the vaccine		
Impact on PAP tests	<i>The only concern I think I would have is that it could potentially make people think they don't need PAPs and once you know, I think it would be easy for people to make that connection like well this is supposed to protect me against the thing that PAP smears test me for so now I don't need PAPs</i>	<i>I made sure that my oldest daughter understood that you know once you became sexually active how important it was to still have your annual exams that just because you had HPV shot doesn't mean I don't ever have to be checked for anything because that is so far from the truth</i>
Facilitators of vaccine acceptance		
Emphasize benefits for cancer prevention	<i>I think if they would have marketed it from day one as a cancer vaccine instead of even using the word sex that they would have a different</i>	<i>This is a vaccine that could possibly prevent my child from having cancer in the future. Why would I not come in here and get this vaccine?"</i>
Strong and personal provider recommendation	<i>One of the things that makes a difference in people getting a vaccine is providers giving a strong recommendation and patients are more likely to get it if you give them kind of a confident recommendation as their provider</i>	<i>Highly recommended it and planned for his own children to have it and he said he strongly recommended it be done</i> <i>Because we are so small, I think they almost value a [provider's] personal opinion as much as they do anything else."</i>
Explain sexual vulnerability of women	<i>I tell parents that y'know, your daughter can be lawfully wed to one man and have sex with that person only and still if he brings the virus into the marriage she's the one that pays the price</i>	<i>When the doctor heard that question [necessity of the vaccine without sexual initiation] his answer was but you don't know about the person you might marry and what they might have done prior to meeting you...I think that was one of the two turning points for me."</i>
Vaccine requirement	<i>If it were required we'd give it more easily, and I have a feeling if it were required some parents wouldn't even ask what it was who might otherwise deny it</i>	<i>Would be okay saying that the government says I have to give you this so suck it up,</i>

These findings provide exploratory validation of the study's hypothesized model (figure 5). The constructs assessed in the integrated behavioral model suggest that individuals who exhibit positive attitudes and low negative perceptions towards the vaccine were more likely to accept it, either as a patient or provider. Additionally, knowledge and awareness about the virus and the vaccine, and the perceived utility of the vaccine in cancer prevention also directly influenced vaccine acceptance. While perceptions of control did not appear to have any influence on vaccine acceptance, perception of existing barriers to affordability of the vaccine and accessibility to health services were predictive of low vaccine acceptance.

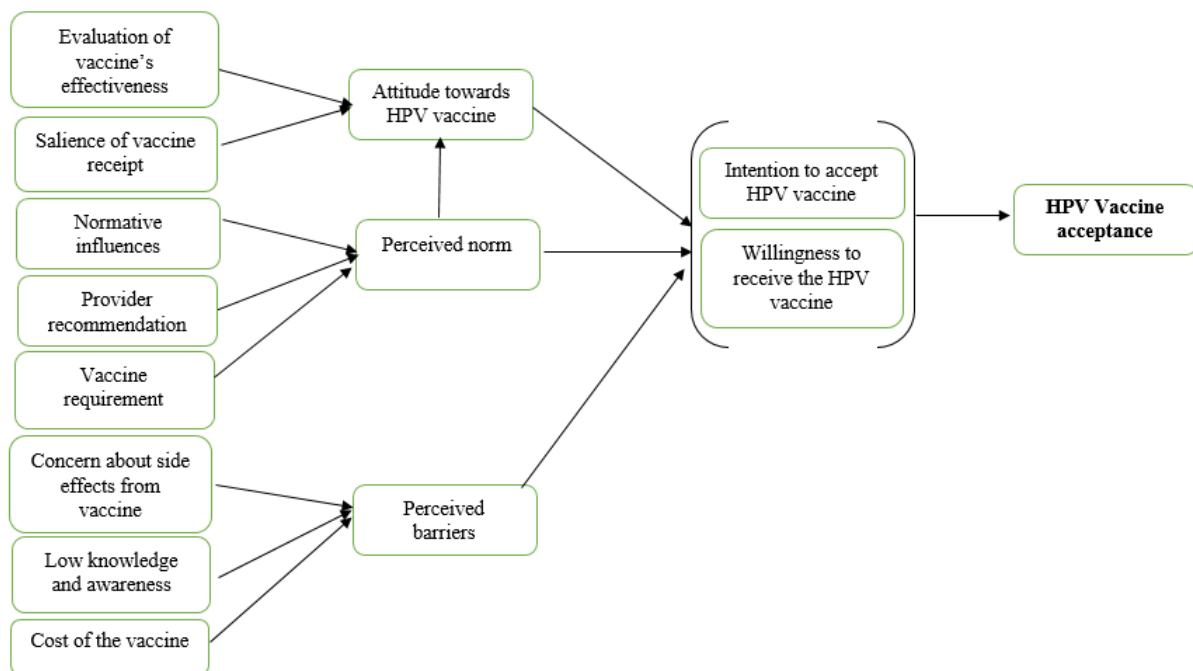


Figure 5: Hypothesized Model of HPV Vaccine Acceptance in Appalachian Tennessee

Exploring vaccine acceptance from a systems perspective reveals convergent barriers and facilitators of vaccine acceptance, across the family context and healthcare sector. In addition, the perception of sex-related topics (e.g., sexual health, sex education, etc.) within Appalachian

Tennessee appears to have subliminal influence on HPV vaccine acceptance among residents of the community (Figure 6).

Summary of Study Findings

Basis for vaccine resistance

Novelty of the vaccine was the most prevalent theme among providers and mothers. Participants' concerns about long-term side effects were often discussed in relation to the period that the vaccine has been existence. Providers often cited parents' resistance to the vaccine based on its relatively recent development. Mothers in the study reaffirmed this belief and drew parallels between the novelty of the vaccine and perceived side effects. They indicated that their concerns about the vaccine's potential side effects and its impact on health and health behaviors were largely due to the novelty of the vaccine and the limited data on longitudinal research.

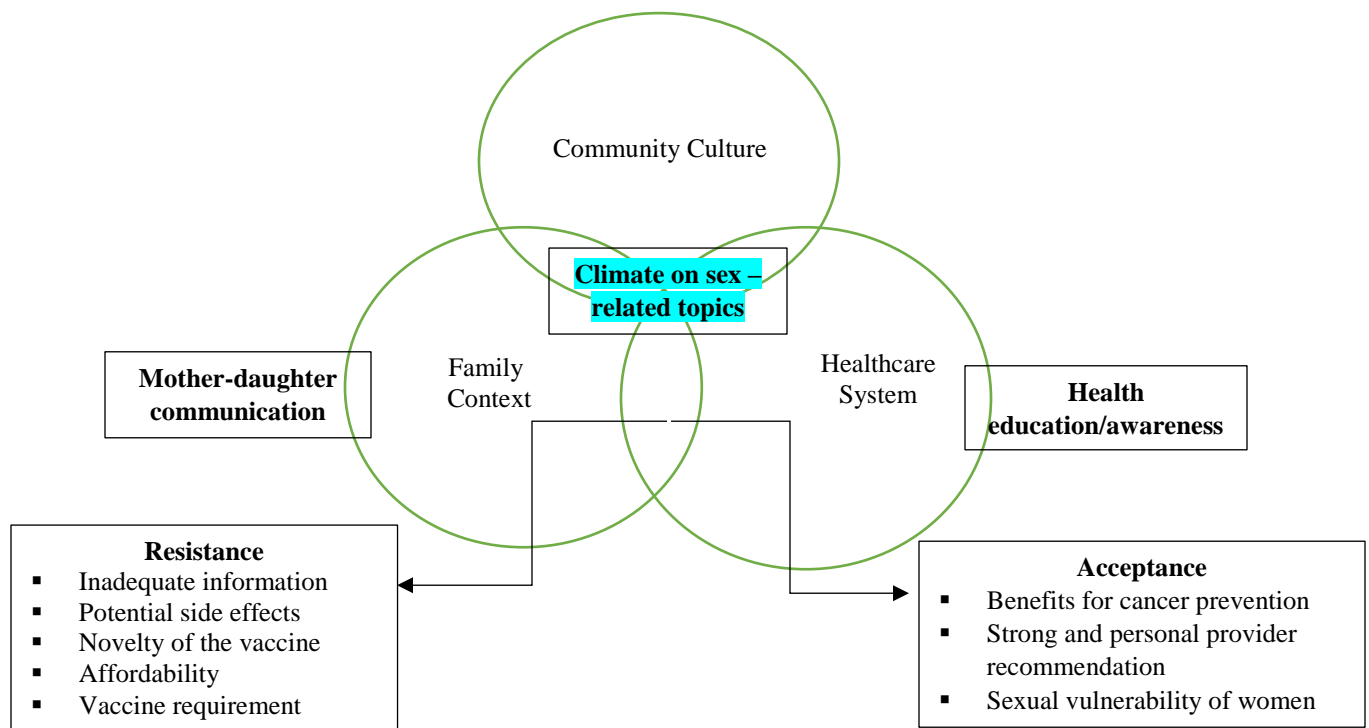


Figure 6: Depicting the Triangulated Findings Using the Multi-Sectorial Model of Systems Thinking

Providers also discussed perceived parental beliefs that the vaccine would encourage sexual initiation and risky sexual behavior; however, mothers in the study denied this belief and instead reported familial and interpersonal perceptions about the vaccine's implication for sexual activity. Also, while none of the mothers reported that they specifically resisted the vaccine because of implied permission for sexual activity, they often indirectly relayed this perception as they discussed refusing or delaying the vaccine based on relevance of the vaccine given their daughter's sexual naiveté. This perception was not limited to parents alone, as some mothers reported that their daughters also questioned the vaccine's necessity because they were not sexually active. To counter this concern, participants in the study report giving (healthcare providers) and receiving (mothers) rebuttals stressing the notion that women are vulnerable to involuntary exposure from unfaithful partners or sexual assault.

Other recurrent themes from the interviews and focus groups indicated that affordability of the vaccine, vaccine safety, the lack of school-entry requirements for the vaccine, and its implication for adolescents' sexual activity were predominant barriers to vaccine acceptance. Results from previous studies indicate that inability to afford the vaccine could inhibit patients, especially those of low SES populations, from receiving the vaccine (Holman et al., 2014). The findings from this study add additional context to this barrier, as participants perceived the high price of the vaccine and emphasized the extent of insurance coverage as a significant determinant of vaccine acceptance. While providers acknowledged this barrier, they were also aware of available resources, within the health department, which could make the vaccine available to uninsured or underinsured patients. However, many parents were unaware of these resources, thus highlighting the gap in availability, accessibility and utilization of health care services.

Congruent with existing reports, individuals who indicated concern about potential side effects from the vaccine were also more likely to resist the vaccine (Hutson et al., 2011a). Across the triad, providers, mothers and young adult women revealed concern about vaccine safety as a barrier to vaccine acceptance. Interestingly, mothers and providers focused on the short-term side effects (pain, fear of needles, adverse reaction) as reasons why parents and adolescents in particular, may resist the vaccine. Only a few participants described specific long-term side effects, and others referred to it as an ‘unknown’ that may occur in the future. Not surprisingly, fear that the vaccine may be detrimental to their child’s health would deter many parents from accepting the vaccine. However, many providers perceived that the existing concern about long-term side effects was due to misinformation, largely propagated by the internet. The status of the vaccine as recommended and not required for school entry appeared to be a barrier, especially from the provider perspective. Providers perceived that if the vaccine were required, there would be less resistance to it, and parents would be less likely to question its effectiveness, safety, and necessity. Mothers also reaffirmed this notion based on the idea that if the vaccine was not required then it wasn't as pertinent.

Finally, in discussing the community’s attitudes towards the vaccine, participants focused on the existence of predominant perceptions about the vaccine's implication on sexual activity. The association of abstinence-only education, both within the school system and community context, and religious values in the region were cited as the foundation for the community resistance. This theme is evident in the contrasting response between the HPV vaccine and other recommended vaccines. As participants noted the similar protective factors of the HPV vaccine and other readily accepted vaccines, and the difference in community acceptance, and inferred

that the perception of implied sexual activity with the vaccine was due to the underlying theme, which deterred acceptance of the HPV vaccine.

Vaccine Acceptance

Receiving a provider's recommendation to get the vaccine emerged as a predominant facilitator of vaccine acceptance across the triad. Providers acknowledged their role and indicated that patients were more likely to receive the vaccine if they recommended it during routine vaccination visits. Mothers reaffirmed this idea, and results from the multivariate analysis indicated that receiving a provider's recommendation was the most significant predictor of vaccine acceptance among young women. While existing studies have illustrated this association, participants in this study particularly highlighted the importance of these recommendations being 'strong and personal.' Participants indicated that recommendations that portrayed the vaccine as a necessity instead of a suggestion, and cited either the provider or a relatable case as an example, had more success in vaccine acceptance. Both providers and mothers noted that among this population, the recommendation was often more effective when received from a trusted healthcare professional with whom a personal relationship has been established. However, as noted by the participants, due to limited accessibility, few residents utilized primary care regularly, thus established provider relationships might not be the norm in the region.

The context in which the recommendation is framed also emerged as a significant factor in vaccine acceptance. Parents and providers reported that the recommendation was often more effective when framed using personal examples, and even more effective when the vaccine's utility in cancer prevention was at the forefront of the recommendation. Many of the mothers discussed weighing the perceived risks and benefits, cancer prevention being the most significant

benefit against which many of the risks were perceived to be minimal. Indeed, parents who had a personal or family history of cancer showed stronger feeling towards the vaccine's utility in cancer prevention.

Mother-Daughter Communication

While many mothers acknowledged the need to engage in sexual health conversations with their daughters, they also perceived difficulty in having these discussions, and instead indicated a preference for sexual health education in schools. Assessment of mother-daughter communication among college-aged women revealed important differences. Compared to those who had not been vaccinated, respondents who had been vaccinated often discussed sexual health and behavior with their mothers and also reported greater satisfaction in their overall communication and relationship with their mothers. While these factors were not significant predictors of vaccine acceptance, they highlight the link between maternal sexual health communication and positive health.

CHAPTER 5

DISCUSSION

Recommendations for Improving Vaccine Acceptance in Appalachian Tennessee

Cervical cancer is a preventable health burden that disparately affects women in rural Appalachia. The HPV vaccine remains the key primary prevention tool to address this health disparity, however, vaccine acceptance rates are lower than expected, particularly among high-risk populations such as residents of Appalachian Tennessee. Previous studies highlight potential barriers to vaccine acceptance; however, many of these studies were conducted in non-Appalachian regions. Considering the ‘distinctiveness’ of each Appalachian sub-region, it is important to recognize the factors that influence vaccine acceptance specific to each region in order to increase vaccination rates. This study, as an exploratory step to investigate HPV vaccine acceptance among key stakeholders – healthcare providers, mothers with adolescent daughters, and young adult women in Appalachian Tennessee – reveals several convergent themes among the triad. These themes particularly highlight the discrepancy in health communication and vaccine policy as leverage points for action (Figure 7).

The existence of negative perceptions about the vaccine’s attributes is largely fueled by the propagation of inaccurate and inadequate health information. Parental concern about the vaccine’s side effects can be attributed to the prevalence of anti-vaccine messages and the sparse availability of accurate scientific information. Therefore, if HPV vaccination rates are to be increased, health communication messages must proactively counter the propagation of false information by debunking the myths and misconceptions about HPV vaccine safety and make this information easily available to the public. This emphasis on communication is further illustrated within the healthcare sector, as the receipt of a provider’s recommendation is a key

predictor of vaccine acceptance. The context in which the recommendation is framed also emerged as a significant factor in vaccine acceptance. Parents and providers reported that the recommendation was often more effective when framed using personal examples, and even more effective when the vaccine's utility in cancer prevention was at the forefront of the recommendation.

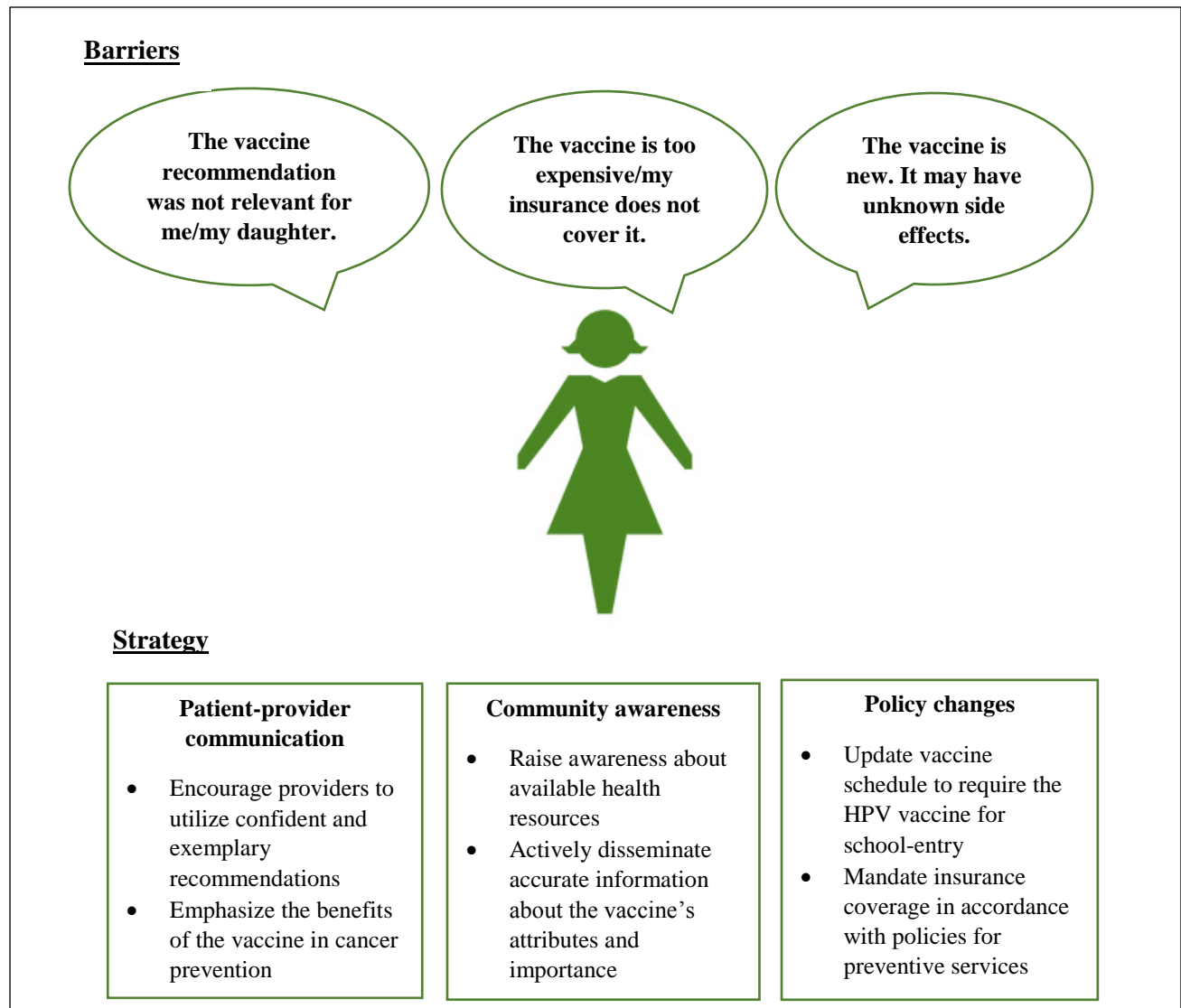


Figure 7: Barriers to HPV Vaccine Acceptance and Potential Strategies for Communication and Policy Change

Facilitation of HPV vaccine acceptance in Appalachian Tennessee would largely benefit from provider messages that emphasize the main objective of the vaccine in preventing cervical cancer. By accurately addressing the issues that are of importance to parents, providers can effectively frame their message to focus on the most significant perceived benefits of vaccine acceptance. Effective health communication messages can also address vaccine resistance based on the perceived implication of vaccine receipt on adolescents' sexual activity. Provider messages that asked parents to consider their daughter's sexual vulnerability appeared to be effective in addressing resistance based on perception of implied sexual activity and should be included in the healthcare provider toolkit to frame recommendations for the HPV vaccine.

The importance of provider-patient communication is additionally evident in the gap between provider awareness about available health resources and lack of patient/community awareness. Therefore, to address vaccine affordability as a barrier, health promotion strategies should encourage communication between providers and patients which ensure that information on health resources are not retained in silos within the healthcare system but are adequately propagated within the community. Health communication messages that raise awareness of available resources within each community and increase ease of accessibility to these resources, so that residents are aware of the need, availability and subsequent provision of the vaccine, would be effective in increasing vaccine acceptance.

These communication messages will also have far-reaching effects if implemented with supportive health policies, particularly policy updates that require the HPV vaccine for school-entry. Including the HPV vaccine along with other mandated vaccines, such as TDaP (Tetanus, Diphtheria and Pertussis), Meningitis, and Hepatitis B, may be an effective way to increase acceptance. These policy changes should be driven by benevolent motivations for vaccine

recommendation, in that cervical cancer is a severe disease which can be prevented, and non-maleficence in regards to the absence of any documented adverse effects from the vaccine which render it unsafe. In comparing HPV infections to similar vaccine-preventable diseases, Hepatitis B is an STI from which we have observed a decrease in incidence rates due to mandated vaccinations (Field & Caplan, 2008). Vaccine requirement adds weight to a provider's recommendation, as parents are more likely to make inference of the necessity and importance of the vaccine if it is required by health care professionals. Updating the vaccine administration schedule would also ensure insurance coverage, as the vaccine would be categorized as a preventive service, and would thus address the concern of cost and affordability.

Study Limitations

The study findings should be interpreted within the context of existing limitations.

Participation Bias

Many of the providers practiced within an academic or health department clinic and agreed to participate on an entirely voluntary basis. Therefore, there is the possibility that those who agreed to participate in the study already had positive attitudes towards the vaccines, and those who declined participation had negative perceptions. This phenomenon could have led to a participation bias in the findings. This study was originally designed to account for this bias through purposeful recruitment of participants from diverse communities. However, recruitment was challenging, and most providers practiced in a single county. Additionally, focus group participants were predominantly of higher education and income level and do not adequately represent the majority of women in Appalachian Tennessee. Moving forward, this bias can be addressed by recruiting a larger and more diverse sample of participants.

Self-reporting Bias

Assessment of vaccine acceptance among the patient population and recommendation among providers was based on self-report, which holds the potential for misrepresentation. Future studies can assess vaccine acceptance by using clinic records to confirm individual reports.

Social Desirability Response

Given the methodology of qualitative research (i.e., face-to-face interviews with healthcare providers), there is the potential that participants provided responses which they deemed socially and professionally acceptable. Also, because of the nature of focus group participation, participants may have felt constricted in openly discussing their opinions and beliefs for fear of judgment. However, given that some of the questions were not sensitive in nature, this bias is expected to have limited effects on the study findings.

Investigator Effect

The investigator's demographic characteristic as an outsider may have influenced the dynamics of the interviews and focus groups, especially considering the region's preference for close-knit interactions. However, this data collection protocol was intrinsic to the scope and purpose of the study.

External Validation

Due to limited resources, data analysis was only conducted by the PI as such coding strategies could not be validated by an additional researcher. Given adequate resources, the study protocol would have included a research assistant to analyze the qualitative data, thus ensuring

the validity of findings. However, the study design incorporated triangulation from different methods to confirm findings from each independent phase in order to increase validation.

Inadequate Survey Items

Finally, although the overarching objective of the study was to explore sociocultural factors of vaccine acceptance in Appalachian Tennessee, the survey measures were not designed to assess these constructs. Future studies can employ validated survey measures that assess cultural identity and associated indices with vaccine acceptance.

Directions for Future Research

This exploratory study is a first step in understanding vaccine acceptance in Appalachian Tennessee. Future studies can build on this work to address the limitations and identify specific predictors of vaccine acceptance among this priority population.

Study 1: Developing an Empirically-Evaluated Instrument to Assess Sociocultural Predictors of HPV Vaccine Acceptable among Appalachian Women

The inadequacy of the survey to assess sociocultural predictors was a major limitation of this study. This was due to the lack of existing instruments to comprehensively assess sociocultural predictors of HPV vaccine acceptable among Appalachian women. Considering the specific perceptions towards the HPV vaccine relative to other vaccines and the unique cultural identity of Appalachian regions, it is important to investigate the predictors of HPV vaccine acceptance specific to the region. Future studies should utilize information from focus groups to develop theory-based items and scales that assess attitudes, perceptions, normative beliefs, indices of Appalachian identity, and cultural norms. The survey could then be refined using qualitative and quantitative content review and cognitive interviews to ensure reliability and

validity of each measure. The final items and scales would then be pilot-tested among mothers who have daughters within the eligible age range for vaccine receipt.

Study 2: Investigating Unvaccinated Young Women

This study explored self-reported vaccination status and associated attitudes and perceptions among college-aged women; however, it did not fully explore correlates of non-vaccine acceptance. For a subsequent study, it would be useful to understand why young women who are otherwise eligible have not been vaccinated. This prospective study can utilize a mixed methods strategy where participants complete the survey developed in Study 1 above and also indicate their vaccination status. Those who report non-vaccination would then be invited to participate in interviews. Ideally, the sampling frame for this study should include a more diverse population of young women across Appalachian Tennessee to ensure a more representative sample.

Study 3: HPV Vaccine Practice and Acceptance among the Triad in a Clinic Setting

The limitation induced by self-reporting of vaccine acceptance was another methodological flaw of this study. To address this bias, another study can utilize a strategy conducted in a clinic setting where providers, mothers and adolescents can be recruited to share their perceptions, beliefs and practices. Using clinic rosters to identify prospective participants, each triad would be approached after a visit where adolescents were eligible to be vaccinated. The study would be introduced and consenting participants would be immediately surveyed using the measurement instrument developed in Study 1 above. Vaccination status would then be validated using patients' records. This study would assess correlates of provider recommendation (i.e., frequency of recommendation, provider attitudes, etc.), and patients' (parent and adolescent) attitudes, perceptions and willingness to accept the vaccine.

Contributions to Public Health

The findings from this study provide foundational insights about HPV vaccine acceptance in Appalachian Tennessee. These findings provide the foundation on which subsequent studies can conduct broader investigations to identify determinants and deterrents of the vaccine in the region. By identifying and understanding factors that are considered beneficial or controversial in the region, health promotion interventions designed to increase awareness and effectively relay the benefits of the HPV vaccine can be tailored to address the specific needs of the community. These strategies would increase vaccination rates and address the cervical cancer disparity among rural Appalachian women

Conclusion

While the HPV vaccine may be gaining acceptance, vaccination rates are still low, largely due to misconceptions about the vaccine's side effects and effectiveness. Major barriers to vaccine acceptance include: cost and age of the vaccine, vaccine safety, the vaccine's requirement status, and its implication for adolescents' sexual activity. Most of these perceptions are driven by the underlying climate on sex-related topics within the larger community. On the other hand, vaccine acceptance in the region is fostered by perceived benefits in cancer prevention and receipt of strong and personal provider recommendations.

Public health efforts to increase vaccination rates should increase awareness about the need for the vaccine and availability of resources. Health education and provider messages should focus on the vaccine's utility in cancer prevention. Future studies should employ validated models and measures to identify the specific predictors of HPV vaccine acceptance in Appalachian Tennessee. Identifying and understanding these factors specific to the region will illustrate the different perspectives of a 'culturally-distinctive' population and highlight the

leverage points for action. These studies will inform the development of future interventions which are crucial to improving HPV vaccination rates, and essential to maximizing the primary benefit of the vaccine in addressing the existing cervical cancer disparity in the region.

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APPENDICES

Appendix A

Interview Invitation Letter

Hello,

My name is Tosin Ariyo, and I am a doctoral student in Community and Behavioral Health at East Tennessee State University (ETSU). I am conducting a study that involves exploring factors that influence the decisions to accept the Human Papilloma Virus (HPV) vaccine for adolescent girls in Northeast Tennessee.

I am looking for clinicians who practice in the Northeast Tennessee region and administer vaccines as part of their clinical practice to join this study which involves participating in an interview and completing a short survey. The interview will last about 30 minutes and will take place at a location of your convenience. Please think about participating. Participation is voluntary. Your input will contribute towards cancer prevention efforts in the region.

If you have any questions or if you're interested in participating, please contact me at ariyoo@mail.etsu.edu or 423-439-4877.

Sincerely,

Tosin Ariyo, DrPH(c), MPH

Appendix B

Focus Group Recruitment Letter

Hello,

My name is Tosin Ariyo. I am a doctoral student in Community and Behavioral Health at East Tennessee State University (ETSU). I am conducting a study that involves exploring factors that influence decisions to accept the Human Papilloma Virus (HPV) vaccine for adolescent girls in Northeast Tennessee.

I am looking for mothers who have daughters between the ages of 11 and 26 years old to enroll in this study which involves participating in a focus group and completing a short survey. The focus group will last about 75 minutes and will take place on the ETSU campus. Please think about participating. Participation is voluntary. Lunch will be provided.

If you have any questions or if you're interested in participating, please contact me at ariyoo@mail.etsu.edu or 423-439-4877.

If you want to learn more about this study or are ready to enroll please follow this link: [Moms HPV Talk](#)

Sincerely,

Tosin Ariyo, DrPH(c), MPH

Appendix C

Mother Eligibility Screener

1. Are you a mom or female caregiver?
 - ☐ Yes
 - ☐ No

2. Do you have a daughter between the ages of 11 to 26 years old?
 - ☐ Yes
 - ☐ No

Appendix D

INFORMED CONSENT (Interviews)

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to voluntarily participate.

- A. Purpose:** The purpose of this research study is to learn about factors that influence the decisions about the Human Papilloma Virus (HPV) vaccine for adolescent girls in the Northeast Tennessee region.
- B. Duration:** This one-time session (including interview and short survey) will last 30 minutes
- C. Procedures:** The procedures, which as a participant in this research will involve you participating in an interview and completing a short survey. The session will be conducted in a private office in your practice and will be audio-recorded.
- D. Alternative Procedures/Treatments.** There are no other options except not to participate.
- E. Possible Risks/Discomforts:** The possible risks and/or discomforts from your participation in this research study include: You may feel minor discomfort answering questions about yourself or your practice. Also, because the session will be audio recorded, there is a potential risk for loss of confidentiality. You have the right to choose not to answer any questions that make you feel uncomfortable and to withdraw from the study at any time.
- F. Possible Benefits:** The possible benefits of your participation in this research study are: as a result of the discussion topics, you may have a better understanding of HPV and communicating with patients about health topics. You will also be directly contributing to future health promotion programs for young women in this region.
- G. Compensation in the Form of Payments to Participant:** There is no compensation in the form of payments for participating in this study.
- H. Voluntary Participation:** Your participation in this research experiment is voluntary. ***You may choose not to participate.*** If you decide to participate in this research study, you can change your mind and quit at any time. If you choose not to participate, or change your mind and quit, the benefits or treatment to which you are otherwise entitled will not be affected. You may quit by calling Tosin Ariyo at 423-439-4877. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about continuing to participate.
- I. Contact for Questions:** If you have any questions, problems, or research-related medical problems at any time, you may call Tosin Ariyo at 423-439-4877, or Dr. Katie Baker at 423-439-6720. You may also call the Chairperson of the ETSU Institutional Review Board at 423.439.6054 for any questions you may have about your rights as a research participant. If you have any questions or concerns about the research and want to talk to someone independent of the

research team or you can't reach the study staff, you may call an IRB Coordinator at 423.439.6055 or 423.439.6002.

- J. Confidentiality:** Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in Lamb Hall Room 310 on ETSU's campus for at least 6 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained, the ETSU IRB, and Tosin Ariyo and her research team have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as described in this form.

You will be given a copy of this consent document for your records.

By signing below, I confirm that I have read and understand this Informed Consent Document and that I had the opportunity to have them explained to me verbally. You will be given a signed copy of this informed consent document. I confirm that I have had the opportunity to ask questions and that all my questions have been answered. By signing below, I confirm that I freely and voluntarily choose to take part in this research study.

Signature of Participant

Date

INFORMED CONSENT (Focus-Group)

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to voluntarily participate.

- A. Purpose:** The purpose of this research study are to:
 - i. Learn about factors that influence the decisions to accept the Human Papilloma Virus (HPV) vaccine for adolescent girls in the Northeast Tennessee region
 - ii. Gain insight on mother-daughter health communication and relationships
- B. Duration:** This one-time session (including focus group and survey) will last 75 minutes
- C. Procedures:** The procedures, which as a participant in this research will involve you participating in a focus group and completing a short survey. The session will take place in a location on ETSU campus and will be audio-recorded.
- D. Alternative Procedures/Treatments:** There are no other options except not to participate.
- E. Possible Risks/Discomforts:** The possible risks and/or discomforts from your participation in this research study include: You may feel discomfort answering questions about yourself and/or your daughter, or talking in a group. Also, because the session will be audio recorded, there is a potential risk for loss of confidentiality. You have the right to choose not to answer any questions that make you feel uncomfortable and to withdraw from the study at any time.
- F. Possible Benefits:** The possible benefits of your participation in this research study are: as a result of the discussion topics, you may have a better understanding of HPV, mother-daughter relationships and communicating with your daughter about health topics. You will also be directly contributing to future health promotion programs for mothers and daughters in this region.
- K. Compensation in the Form of Payments to Participant:** There is no compensation in the form of payments for participating in this study.
- L. Voluntary Participation:** Your participation in this research experiment is voluntary. ***You may choose not to participate.*** If you decide to participate in this research study, you can change your mind and quit at any time. If you choose not to participate, or change your mind and quit, the benefits or treatment to which you are otherwise entitled will not be affected. You may quit by calling Tosin Ariyo at 423-439-4877. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about continuing to participate.
- M. Contact for Questions:** If you have any questions, problems, or research-related medical problems at any time, you may call Tosin Ariyo at 423-439-4877, or Dr. Katie Baker at 423-439-6720. You may also call the Chairperson of the ETSU Institutional Review Board at 423.439.6054 for any questions you may have about your rights as a research participant. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423.439.6055 or 423.439.6002.

- N. Confidentiality:** Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in Lamb Hall Room 310 on ETSU's campus for at least 6 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a participant. Although your rights and privacy will be maintained, the ETSU IRB, and Tosin Ariyo and her research team have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as described in this form.

You will be given a copy of this consent document for your records.

By signing below, I confirm that I have read and understand this Informed Consent Document and that I had the opportunity to have them explained to me verbally. You will be given a signed copy of this informed consent document. I confirm that I have had the opportunity to ask questions and that all my questions have been answered. By signing below, I confirm that I freely and voluntarily choose to take part in this research study.

Signature of Participant

Date

Informed Consent (Survey)

Dear Participant:

My name is Tosin Ariyo and I am a doctoral student at East Tennessee State University. I am working on my DrPH in Community and Behavioral Health. As part of my dissertation, I am completing a study on women's health. The name of my research study is 'Women's Sexual Health and Communication.'

The purpose of this study is to assess young women's perceptions of their sexual and reproductive health, gender roles and their primary mode of sexual health communication. I would like to give a brief online survey to ETSU female college students using Survey Monkey. It should only take about 30 minutes to complete. Since the survey is administered through Survey Monkey, your SONA ID will be required in order to be awarded participation credit. You will be asked questions about your demographic information, prior sexual behaviors, knowledge, attitudes, and beliefs regarding sexual behaviors, perceived health risks, and gender norms. Since this project deals with personal behavior and feelings, it might cause some minor stress. However, you may also feel better after you have had the opportunity to express yourselves about your opinions and experiences. This study does not provide any direct benefit.

Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties, as is the case with emails. In other words, we will make every effort to ensure that your name is not connected with your responses. Specifically, Survey monkey has security features that will be enabled: IP addresses will not be collected and SSL encryption software will be utilized. Although your rights and privacy will be maintained, the ETSU IRB (for non-medical research) and personnel particular to this research, in the Community and behavioral health department, have access to the study records.

If you do not want to fill out the survey, it will not affect you in any way. You may skip any questions you do not wish to answer or simply exit the online survey form if you wish to remove yourself entirely.

Participation in this study is voluntary. You may refuse to participate. You can quit at any time. If you quit or refuse to participate, the benefits or treatment to which you are otherwise entitled will not be affected.

If you have any research-related questions or problems, you may contact me, Tosin Ariyo at (423) 439-4877. I am working on this project together under the supervision of Dr. Katie Baker. You may reach her at (423) 439 6720. Also, the chairperson of the Institutional Review Board at East Tennessee State University is available at (423) 439-6054 if you have questions about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423/439-6055 or 423/439/6002.

Sincerely,

Tosin Ariyo, DrPH(c), MPH

Clicking the AGREE button below indicates:

- You have read the above information
- You voluntarily agree to participate
- You are at least 18 years of age or older

☐ I AGREE

☐ I DO NOT AGREE

Appendix E

Provider Demographic Survey

1. What is your gender
 - ☐ Female
 - ☐ Male
2. What is your clinical degree?
 - ☐ LPN
 - ☐ RN
 - ☐ BSN
 - ☐ MSN
 - ☐ DNP
 - ☐ MD
 - ☐ DO
3. Please select your area of practice?
 - ☐ Family medicine
 - ☐ Internal medicine
 - ☐ Pediatrics
 - ☐ Ob-Gyn
4. How many years have you been in practice?
 - ☐ Less than 5
 - ☐ 5-10
 - ☐ 10-15
 - ☐ 15-20
 - ☐ 20 or more
5. How would you describe your practice setting?
 - ☐ Academic
 - ☐ Clinic
 - ☐ Hospital
 - ☐ Other_____
6. What county is your practice located?

7. Do you identify as Appalachian?
 - ☐ Yes
 - ☐ No
8. Do you often recommend the HPV vaccine to your patients (or their parents)?
 - ☐ Yes
 - ☐ No

Appendix F

Semi-Structured Interview Guide

Date: _____

Time Started: _____

Thank you for agreeing to speak with me today. To get started...

1. Could you tell me about your practice, such as the kinds of patients you see? Demographics? Age-ranges?
2. Are vaccinations part of your routine care for patients?
3. Could you describe how the vaccination process works in your practice?

Probes:

- a. Are there certain mechanisms within your practice that prompt the staff to suggest vaccines to patients? (Recall/reminder prompts?)
 - b. Who in the practice usually does the vaccinating (nurses? Medical assistants?)
 - c. How does vaccination get introduced to parents/patients?
 - d. Do you feel that there are differences in vaccinating older kids versus the early childhood patients?
4. Who decides what vaccinations your patients receive?
 5. Are there any barriers for the clinic to providing vaccines?

Probes:

- a. Cost?
 - b. Availability?
 - c. Could you expand on these limitations?
6. What kinds of discussions do you have with parents/patients about newer vaccines, if any?
 7. Do you actively recommend specific vaccines? If so, what guides your vaccine recommendations?
 8. What do you think about these vaccines are important or useful for your patient population?

Probes:

- a. Does this population have specific health needs or concerns?
 - b. How do you assess this?
9. How do you convey to parents the importance of these vaccines?
 10. Do you ever have adolescents, themselves, ask for specific vaccines?

HPV specific

11. Could you tell me a little about your experience with the HPV vaccine?
12. What do you think about the vaccine?
13. What concerns do you have, as a practitioner, or personally, about the HPV vaccine?
14. Do you usually recommend the vaccine to parents or their daughters?
 - a. Could you tell me about how you introduce the vaccine to them?
15. Do you encounter any concerns from parents or teenagers about the HPV vaccine?
16. What is the main reason parents in your practice don't get the HPV vaccine for their daughters?
17. Is HPV-related disease something you see in your patient population?
18. Do you talk to parents or patients about STIs more generally? Is that a discussion you have when talking about the HPV vaccine?
19. What do you tell your patients or parents about HPV? Do you discuss HPV independently of discussing the vaccine? Why or why not?

Probe:

 - a. Mention of cervical cancer? Genital warts?
20. Do you give the HPV vaccine to your patients? How often?

Probe:

 - a. Do patients ask for the vaccine?
 - b. Do parents ask for the vaccine?
 - c. Are parents or boys/girls more likely to ask for the vaccine?
 - d. Do you get adolescents coming in requesting the vaccine on their own?
21. Could you describe for me the way in which you introduce the HPV vaccine to your patients or their parents?
22. Are you aware that there are currently three HPV vaccines?
23. How do you decide which vaccine to provide your patients?
24. Once you have given the first HPV shot, how do you get patients to return for boosters? What sorts of techniques have you found useful?
25. What are some of the prompts, in your opinion, that might lead to parents asking for the vaccine?
26. Are there specific groups of patients that you would say are less receptive to the HPV vaccine?
27. What are some of the reasons your patients don't accept the vaccine?
28. How do you address these reasons?
29. Can you recommend another staff person here to interview?

ARE YOU A MOM?



Do you have a daughter between the ages of 11-26 years old?

...You may be able to participate in a one-time focus group session.

Lunch will be provided.

The purpose of this focus group is to understand factors that influence the decisions to accept the Human Papilloma Virus (HPV) vaccine for adolescent girls in the Northeast Tennessee region

The session will last approximately 75 minutes

Appendix G

Mother Demographic Survey

1. What is your county of primary residence?

2. Do you identify as Appalachian?

- ☐ Yes
- ☐ No

3. What is your age? (Please enter number in years)

4. What is your marital status?

- ☐ Married
- ☐ Divorced
- ☐ Widowed
- ☐ Separated
- ☐ Never married

5. What is your highest education level?

- ☐ Less than high school
- ☐ High school diploma/GED
- ☐ Associate degree
- ☐ Some College
- ☐ College degree
- ☐ Graduate degree
- ☐ Professional degree

6. Are you currently?

- ☐ Employed Full-time
- ☐ Employed part-time
- ☐ Student
- ☐ Homemaker
- ☐ Student
- ☐ Unemployed
- ☐ Retired

7. What is your estimated household income?

- ☐ Less than \$20,000
- ☐ \$20,000-\$34,999
- ☐ \$35,000-\$50,000

- ☐ \$50,000-\$75,000
 - ☐ \$75,000 or more
- 8. Is your family covered by any kind of health insurance or some other kind of health care plan?
 - ☐ Yes
 - ☐ No
- 9. If yes, what kind of health coverage do you have?
 - ☐ Private health insurance
 - ☐ Employee health insurance
 - ☐ Medicaid
 - ☐ SCHIP (CHIP/Children's Health Insurance Program)
 - ☐ Military health care (TRICARE/VA/CHAMP-VA)
 - ☐ Indian Health Service
 - ☐ State-sponsored health plan
 - ☐ Other government program
 - ☐ Single service plan (e.g., dental, vision, prescriptions)
 - ☐ Employee health insurance
- 10. My healthcare provider recommended the HPV vaccine for my...
 - ☐ Daughter
 - ☐ Son
 - ☐ Both
 - ☐ The vaccine has not been recommended
- 11. Has your daughter received the HPV vaccine?
 - ☐ Yes
 - ☐ No
- 12. Have you or anyone in your family ever being diagnosed with cervical cancer?
 - ☐ Yes
 - ☐ No

Appendix H

Focus Group Guide

Cervical cancer awareness and knowledge

- What do you know about cervical cancer?
- What do you think when you hear cervical cancer?
- Do you worry about cervical cancer for yourself? Your daughter?
 - Why? Why not?

HPV Awareness and knowledge

- Before today had you heard about HPV?
- What did you hear about it?
- Do you worry about your children getting HPV?
- Have you heard about the vaccine?
- What do you know about the vaccine?

Attitudes towards HPV vaccine

- What are your thoughts about the vaccine?
- Why would you (would you not) choose to vaccinate your daughter?
- What concerns would you have about vaccinating your daughter?
- What is the main reason you (will) choose to get the HPV vaccine for you daughter(s)?
- Would you say vaccinating your daughter is beyond your control?

Sources of information

- Where do you get health information?
- Do you talk to your daughter about her health?
 - What do you talk about
- Have you talked to your healthcare provider about the HPV vaccine?
 - How was the conversation?
- Do you talk about the HPV vaccine or cervical cancer within your social circles (friends, family etc.)?

Healthcare access

- Who is responsible for healthcare decisions in your household?
- If you wanted to vaccinate your daughter, what obstacles do you think you would encounter? / When you vaccinated you daughter did you encounter any obstacles? What were there?

Perceived Norms

- How do you think people within your social circles would feel about you vaccinating (or not vaccinating) your daughter?
- In thinking about your communities, what do you think is the general attitude towards the HPV vaccine

Appendix I

Women's Sexual Health and Communication Survey: SONA Survey

Screenener

1. Gender at birth?
 - ☐ Male
 - ☐ Female

Demographics

2. Enter your SONA ID? _____
3. How old are you? (Years)
 - ☐ 18-22
 - ☐ 23-26
 - ☐ 27-30
 - ☐ 30+
4. Are you Hispanic or Latino?
 - ☐ Yes
 - ☐ No
5. What is your race? (Select one or more responses):
 - ☐ African-American/Black
 - ☐ American-Indian/Alaska Native
 - ☐ Asian
 - ☐ Caucasian; Non-Hispanic White
 - ☐ Native Hawaiian/Pacific Islander
6. In what type of environment have you spent most of your life?
 - ☐ Rural
 - ☐ Urban

- Suburban
- 7. In what county did you reside for the majority of your childhood?

- 8. Do you identify as Appalachian?
 - Yes
 - No

Health Education

Sexual and reproductive health involves all matters relating to the reproductive system. It implies the ability to have a satisfying and safe sex life, the capability to reproduce, and the freedom to decide if, when, and how often to do so.

- 9. Have you ever received any formal instruction at school, church, a community center or some other place about sexual abstinence?
 - Yes
 - No
- 10. Have you ever received any formal instruction at school, church, a community center or some other place about methods of birth control?
 - Yes
 - No

Sexual Health

- 11. How old were you when you had your first menstrual period? (Years)

- 12. Have you ever had sexual intercourse? (This could be either anal, oral or vaginal)
 - Yes
 - No [skip to #23]
- 13. At what age did you have your first sexual intercourse? (This could be either anal, oral or vaginal)Years

14. Which came first, your first sexual intercourse or your first menstrual period?
- ☐ Sexual intercourse
 - ☐ Menstrual period
15. Have you ever been told by a doctor or nurse that you had a sexually transmitted disease such as genital herpes, genital warts, chlamydia, syphilis, gonorrhea, AIDS, or HIV infection?
- ☐ Yes
 - ☐ No
16. Since your first menstrual period have you ever visited a clinic for (and received) any kind of reproductive health or birth control service?
- ☐ Yes
 - ☐ No [Skip to #23]
17. Did you receive formal education at school, church, a community center or some other place about sexual abstinence before or after your first sexual intercourse?
- ☐ Before
 - ☐ After
18. Did you receive formal education at school, church, a community center or some other place about methods of birth control before or after your first sexual intercourse?
- ☐ Before
 - ☐ After
19. Have you ever had a Pap smear or Pap test?
- ☐ Yes
 - ☐ No [skip to #34]
20. What was the main reason you had this Pap test?
- ☐ Routine Pap test
 - ☐ Routine physical

- Last pap test was not normal
- A specific problem
- Never had one and thought you should
- Pre/Post-natal visit
- Other _____

21. Was this before or after your first sexual intercourse?

- Before
- After
- Not Applicable

22. Have you ever been pregnant?

- Yes
- No

Perception of gender roles

Please tell us how strongly you agree with the following statements

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
23. Women who carry condoms are easy.					
24. Men should decide what type of sex to have.					
25. It is a woman's responsibility to avoid getting pregnant.					
26. Swearing and obscenities are more repulsive when stated by women compared to men.					
27. The intellectual leadership of a community should be largely in the hands of men.					
28. The father should have greater authority than the mother when raising children.					

29. There are many jobs in which men should be given preference over women in being hired or promoted.					
30. In my opinion, a woman can suggest using condoms just like a man can.					
31. A man and a woman should decide together what type of contraception to use.					

Cervical Cancer knowledge

32. What have you heard are the causes of cervical cancer?

- ☐ Smoking
- ☐ Virus
- ☐ STI/STD
- ☐ Other_____

33. Is cervical cancer preventable?

- ☐ Yes
- ☐ No

34. How can you prevent cervical cancer? [Select all that apply]

- ☐ Safe sex
- ☐ Vaccine
- ☐ Pap Smear

Cervical Cancer attitudes

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
35. Cancer of the cervix is most times fatal.					
36. Cancer of any kind is a death sentence.					

37. Cancer of the cervix is beyond my control.					
38. Cancer is a disease that cannot be avoided.					
39. Faith will help me prevent disease and death.					

HPV Knowledge and Perceptions

40. Have you heard about the Human Papilloma virus (HPV)? It is not HIV, HSV, or herpes.

- ☐ Yes
- ☐ No

41. Where did you get the information?

- ☐ Healthcare provider
- ☐ Maternal figure
- ☐ Other family member
- ☐ Friends
- ☐ Media (TV, Flyers, Ads)
- ☐ School

42. Have you ever been told by a healthcare provider that you had an HPV infection?

- ☐ Yes
- ☐ No

43. Who can get HPV?

- ☐ Males
- ☐ Females

44. HPV is transmitted skin-to-skin.

- ☐ True
- ☐ False

45. HPV is sexually transmitted.

- ☐ True
- ☐ False

46. HPV can be transmitted even without exhibited signs or symptoms.

- ☐ True
- ☐ False

47. Most people with HPV have no symptoms.

- ☐ True
- ☐ False

48. HPV can be prevented.

- ☐ True
- ☐ False

49. Condoms can prevent HPV.

- ☐ True
- ☐ False

50. There is a vaccine to prevent HPV.

- ☐ True
- ☐ False

51. HPV can cause_____ (Select all that apply)

- ☐ Cervical cancer
- ☐ Genital warts
- ☐ Penile cancer
- ☐ Oral Cancer
- ☐ Other?

52. HPV can go away without any treatment.

- ☐ True
- ☐ False

HPV Attitudes

	Strongly Agree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
53. I can get HPV					
54. The vaccine cannot really prevent HPV.					
55. I am worried about side effects from the vaccine.					

HPV Vaccination

56. Have you received the cervical cancer vaccine, also known as the HPV shot, Cervarix, or Gardasil?

- ☐ Yes
- ☐ No {Skip to #63}

57. How many doses have you received?

- ☐ 1
- ☐ 2
- ☐ 3

58. How old were you when you received your first HPV vaccine shot? (Years)

59. Which occurred first-your first sexual intercourse or your first HPV vaccine shot?

- ☐ Yes
- ☐ No
- ☐ Not Applicable

60. Perceived Control

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
1. For me to receive the HPV vaccine is easy					
2. The decision to receive the vaccine is beyond my control					
3. Whether I get vaccinated or not is not entirely up to me					

61. Perceived Norm

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
1. Most people who are important to me think I should receive the HPV vaccine					
2. Most people who are important to me think it would be a good idea to receive the HPV vaccine					
3. Most people who are important to me want me to get the HPV vaccine					

62. Vaccine intention

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
1. I expect to receive the HPV vaccine					
2. I want to receive the HPV vaccine					
3. I intend to be vaccinated against HPV					

Maternal Communication

63. What is your relationship to the person in your life that has been most like a mother to you?

- ☐ Biological Mother
- ☐ Stepmother
- ☐ Adoptive Mother
- ☐ Other female mother figure or guardian

64. Have you and your 'mother' talked about [check all that apply]

- ☐ Cervical Cancer
- ☐ HPV
- ☐ HPV Vaccine

65. Maternal Endorsement

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree
1. My mother thinks I should receive the HPV vaccine					
2. My mother thinks it would be a good idea to receive the HPV vaccine					
3. My mother wants me to get the HPV vaccine					

We are interested in how you communicate with your mother. Please indicate whether you have discussed the following topics with your mother.

As a teenager, my mother talked with me about...

	Yes	No
4. The importance of not being pressured to engage in sexual activity		
5. Sexual health in general (Including but not limited to sexual behavior, safe sex practices etc.)		
6. Birth control		
7. Sexually transmitted diseases		
8. Safe sex practices		
9. Sexual intercourse		
10. Abstinence		
11. The warning signs for cervical cancers		
12. HPV Vaccination		
13. Cervical cancer screening (Pap smears, HPV tests)		
14. Violence against women		

Please indicate your perception of how receptive you were to your communication about each topic using the scale shown below, indicating whether you disagree or agree. If you have not talked with your mother about a topic, please choose "we have not talked about it."

I was receptive when my mother and I talked about...

	Strongly Disagree	Moderately Disagree	Neither agree nor disagree	Moderately Agree	Strongly Agree	We have not talked about it
15. The importance of not being pressured to engage in sexual activity						
16. Sexual health in general (Including but not limited to sexual behavior, safe sex practices etc.)						
17. Birth control						
18. Sexually transmitted diseases						
19. Safe sex practices						
20. Sexual intercourse						
21. Abstinence						
22. The warning signs for cervical cancers						
23. HPV Vaccination						
24. Cervical cancer screening (Pap smears, HPV tests)						
25. Violence against women						

Please answer these questions with respect to your relationship with your mother figure you indicated earlier.

We are interested in the characteristics of your relationship with your mother. Please indicate how much you agree or disagree with the following statements by checking one box in each row.

Mother-Daughter Relationship

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
26. When we talk about important topics, my mother has something useful to say.					
27. My mother gives me good advice.					
28. The advice my mother gives me is helpful when we talk about important topics.					
29. I go to my mother for help when I need advice about something important.					
30. My mother knows a lot about things that are important to me.					
31. I know that my mother wants what is best for me.					
32. My mother keeps her promises to me.					
33. I can trust my mother when we talk.					
34. My mother is honest with me.					
35. My mother is there for me when I want to talk to her.					
36. My mother understands my problems and worries.					
37. My mother lets me make my own decisions.					
38. Overall, I am satisfied with the way my mother and I communicate.					
39. When we talk about important topics, my mother wants to hear what I have to say and think.					

40. When I talk about important things with my mother, she tells me about her past experiences.					
41. When I talk about important things with my mother, she tells me things about her life, even if they are embarrassing.					
42. When I talk about important things with my mother, she tells me what things were like for her when she was my age.					
43. My mother is good about not “lecturing” me too much.					
44. It is difficult for my mother and me to find time to talk.					
45. My mother is too busy when I want to talk.					

VITA
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MPH Community Health Practice, University of Texas Health
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- Experience:** **Graduate Research Assistant**, East Tennessee State University
College of Public Health- Cancer Prevention Lab,
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Teaching Associate, East Tennessee State University
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Doctoral Intern, WHO- Lusaka, Zambia, June-August 2015
Research Assistant, Levine Cancer Institute; Charlotte,
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Surveillance Evaluation Researcher, Fort Bend County Dept. Of
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Teaching Assistant, UTHSC-School of Public Health, Houston,
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Graduate Research Assistant, UTHSC-Fort Bend Co. Tobacco
Coalition, Houston, Texas, March-May 2013
Intern, USDA/ARS Children's Nutrition Research Centre- *MEND*
Project, Houston, Texas, December 2012-May 2013
Data Collector, UTHSC-*Shape-Up Houston; Texas CORD*
Project, Houston, Texas, March-December 2012
Data Collector, ETR Associates- *It's Your Game* Project,
Houston, Texas, August-December 2012
Research Assistant, Lee University/University of Tennessee-
College of Medicine, May-July 2010
Peer Leader, Lee University; Cleveland, Tennessee, 2009-2010
- Publications:** ***Presentations***
Emily Benham, Joshua Hill, Kendall Carpenter, **Oluwatosin Ariyo**, Yimei Han, Meghan Forster, Terry Sarantou, Richard L White. Jr:
National Implementation of Mitotic Rates In Cutaneous Melanoma: An Investigation Using the National Cancer

Database. NC-American College of Surgeons- Residents Research; July 2014

Hill JS, Carpenter KW, **Ariyo O**, Han Y, Riggs SB, Salo JC:
Epidural Catheter Use for the management of Post-Operative pain in a National Review of Cancer Surgeries: Utilization, benefits and Complications. American College of Surgeons Clinical Congress; October 2014

Tosin Ariyo, Megan Quinn, L. Carter Florence:
Demographic and Socioeconomic Correlates of Pediatric Melanoma Incidence from 1973-2011. Appalachian Student Research Forum; April 2015

Florence, LC, Hillhouse, JJ, Oleski, J, Pagoto, S, **Ariyo, T**:
Prevention of Skin Cancer and Preference of Tanning Location. Poster presentation at the Appalachian Student Research Forum Johnson City, TN; April 9, 2015

Ariyo, O., Baker, K., Peluso, A., Florence, L.C.:
Supporting the Case for a Maternal Social Media Campaign to Reduce Indoor Tanning Among Teenage Girls. Appalachian Student Research Forum, Johnson City, TN. April 2016

Tosin Ariyo, Katie Baker, Ruby Yadav:
Correlates of HPV Vaccine Acceptance among College Women in East Tennessee. Poster presentation at the Tennessee Public Health Association Annual Conference, Nashville TN; September 2016.

Tosin Ariyo, Katie Baker:
Sociocultural Correlates of Human Papilloma Virus Vaccine Uptake among College Women in East Tennessee. Poster presentation at the Association of Maternal and Child Health Programs Annual Conference, Kansas City, MO; March 2017.

Honors and Awards:

Delta Omega- Alpha Pi Chapter Inductee, 2017
Chair's Award for Excellence in Service, 2017
PEO International Peace Scholarship, 2016
Frist Global Health Leader Scholarship, 2015
Honors College Study-Abroad Scholarship 2015
PHI KAPPA PHI-Honors Society
Endowed Scholar: UTHSC-School of Public Health, 2012
Who's Who in American Colleges and Universities, 2011
PHI ETA SIGMA- Honors Society
Presidential Scholar: Lee University 2007-2011